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Multimorbidity in the Context **O**f **S**ocioeconomic Deprivation: **A** mixed methods exploration of how **I**ndividual and **C**ommunity factors interact to influence patient capacity to manage Multimorbidity **(MOSAIC).**

Dr Marianne Rankin McCallum
BSc MBChB MRCGP MSc

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School of Health and Wellbeing

College of Medicine, Veterinary Medicine and Life Sciences

University of Glasgow

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Abstract

Background: Despite significant investment in research and resource, health inequalities persist and in some cases are worsening. Multimorbidity (presence of two or more long-term conditions in an individual) is more prevalent in areas of high socioeconomic deprivation, where it begins at an earlier age. Burden of Treatment Theory (BOTT) states that where the work of managing chronic conditions (treatment burden) outweighs the capacity to carry out that work, poorer outcomes persist. Preliminary research has explored treatment burden in the context of multimorbidity, but capacity remains under-researched. Given that factors known to reduce capacity cluster in areas of high socioeconomic deprivation, understanding capacity, and how to support and enhance it, has the potential to inform the design of services that may narrow existing health inequalities. This thesis aims to explore, and begin to quantify, the influence of key capacity impacting factors on the ability to self-manage multimorbidity in the context of socio-economic deprivation and to understand how individual and community level factors interact to influence health self-management decisions.

Methods: A multi-methods approach that employed three work packages. 1) A systematic review of existing multimorbidity interventions which employed two methods of data analysis: a meta-ethnography of participant experience and a framework analysis underpinned by BOTT. 2) A quantitative analysis of cohort data exploring the association between individual and community capacity factors, treatment burden and mortality and hospital admissions in people living with multimorbidity 3) A qualitative exploration of the experience of living with multimorbidity in one community experiencing high socioeconomic deprivation. An ethnographically informed approach was taken including 25 in-depth interviews, one focus group, 142 hours of participant observation in four community groups and two participatory workshops. An initial broad thematic descriptive analysis was followed by an analytical synthesis of the themes, exploring how they related to each other and the existing BOTT constructs.

Main Findings: 1) Current multimorbidity interventions focus primarily on practitioner experience or on narrow aspects of participant experiences of interventions. They rarely consider the experience of those who did not benefit. Person-centred care, an objective for several interventions, was often practitioner defined. While interventions could initially shift care to be more person-centred, organisational factors meant this was often not sustained and reverted to usual care. Interventions benefit from a clear evidence-based structure and practitioner training and supervision increase the likelihood of implementation as intended. In addition, interventions that had flexible components, or were able to include flexibility in application, appear to be more effective in engagement. BOTT constructs and social context were not routinely considered by current interventions, and none considered the impact of the work of the intervention for patients with multimorbidity. 2) BOTT constructs can provide a framework to explore capacity variables at the population level. Capacity measures vary over time; not adjusting for this in the analysis could potentially over-estimate or miss associations. As well as expected associations between known individual factors such as literacy, housing tenancy or disability, there was a potential association between mortality and the extent to which people feel they have control over their health, although the exact relationship is unclear (e.g. for the statement “I have little control over what happens to me”: Agree strongly reference group 1; compared to agree 0.51 (0.27,0.98); Disagree 0.47 (0.25,0.90); Disagree strongly 0.57 (0.28,1.14)). In addition, compared to never walking in the dark (reference group 1) there was a protective association with mortality for those who tried to avoid (0.70 (0.57,0.87)), felt uncomfortable (0.66 (0.52,0.84)) or who had no worries (0.63 (0.53,0.76)). This association was also seen for hospital admissions for those who felt uncomfortable (0.61 (0.45,0.83) or who had no worries (0.71 (0.55,0.91)). 3) Qualitative findings demonstrated that BOTT constructs were useful in understanding individual capacity to manage multimorbidity in the context of high socioeconomic deprivation. However, additional components, such as the role of biography (maintaining personal identity) and grounding activities do not fully align with current BOTT constructs. In addition, participants described shared community experiences of “being known” in the community, the experience of stigma , antisocial behaviour, a rundown physical environment, and none of the systems working for them. These experiences influenced how participants accessed healthcare, and their self-management decisions and capabilities. This was summarised as a new construct “community capacity”: the unconscious internalisation of wider shared community experiences. In the context of high socioeconomic deprivation community capacity shaped, and sometimes constrained, individual capacity. Finally, the ethos of community groups (authentic, safe space, peer support, challenge) and high-quality person-centred care were particularly enabling, in part because of their ability to ameliorate the influence of community capacity.

Conclusions: Both individual and community factors have a critical impact on the capacity to manage multimorbidity, and some of these capacity factors are associated with mortality and hospital admissions. BOTT constructs can be used to measure associations between capacity factors at the population level, and this could be built on to create a validated measure of capacity. Health services, and future interventions, should prioritise supporting and optimising person-centred care, work with communities to ensure services are authentic safe spaces and consider utilising peer support for people living with multimorbidity in areas of high socioeconomic deprivation. As community capacity shapes individual capacity, applying BOTT in the context of high socioeconomic deprivation without consideration of wider contextual, community factors, risks perpetuating and widening existing health inequalities. However, an extended BOTT incorporating community capacity, biography and being grounded could be utilised in a high socioeconomic deprivation context to help design health services and interventions for people living with multimorbidity. Such services have the potential to improve outcomes and narrow health inequalities in this setting.

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Author’s Declaration

I declare that I am the sole author of this thesis and was responsible for leading all aspects of this research, unless otherwise stated, under the guidance and support from my supervisors. A number of colleagues collaborated at various stages, and they are formally acknowledged below.

Systematic Review

I acknowledge the support of Paul Cannon, information scientist at Glasgow University library who advised me on search strategies and how to adapt the one identified. I acted as first reviewer during all stages of the review including paper screening, data extraction, quality appraisal and analysis. Sara Macdonald, Guy Rughani, Naeve Corcoran, Oscar Ponce, Caitlin Jones, Tiffany Sophie Keep and Timeyin Ejuoneatse all acted as second reviewers for screening and data extraction.

Quantitative Data Analysis

The West of Scotland Twenty-07 Cohort data was provided with permission from the MRC/CSO Social and Public Health Sciences Unit, University of Glasgow. Mary-Kate Hannah (data scientist, MRC Social and Public Health Sciences Unit, University of Glasgow) created the dataset from the original cohort data based on my requests for variables. Both herself and Dr Katherine Skivington advised on questions arising regarding data collection and existing cohort variables as required (MRC Social and Public Health Sciences Unit, University of Glasgow).

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Recruitment for the in-depth interviews was co-ordinated by Tracy Ibbotson from West node of the Scottish Primary Care Research Network.

Presentations and Papers

Publications

MacFarlane A, **McCallum M** and Stewart M (2023). Improving person-centered care for people with multimorbidity: the potential of participatory learning and action research Journal of Multimorbidity and Comorbidity 2023 Vol. 13 DOI: 10.1177/26335565231207075

Selected Presentations

M McCallum, Mair F, Ponce O, Raghani G, Keep T, Corcoran N, Macdonald S. Patient centred care in an evidence-based world? A meta-ethnography of multimorbidity interventions. *North American Primary Research Group Annual Scientific Meeting*. Online; November, 2021 (Oral Presentation)

- **Winner Distinguished Paper Oral Presentation at the North American Primary Care Research Group (NAPCRG) Annual Meeting Online 2021**

McCallum M, Mair F, MacDonald S When all the systems fail: the burden of managing health in socioeconomically deprived communities. *Reseau 1 (Annual Scientific Meeting of Quebec Primary Care Research Network)*. Montreal, Canada; July 2022

- **Keynote speaker, one of several presentations conducted as part of time spent at McGill University Montreal after securing funding via University of Glasgow Early Career Mobility Scheme**

McCallum M, Mair F, Macdonald S. Making it work": How community groups create space for behaviour change. *North American Primary Research Group Annual Scientific Meeting(NAPCRG)*. Phoenix, USA; November 2022 (Oral Presentation)

- **Winner NAPCRG-Dutch College reciprocal award for outstanding research.**

McCallum M, Stewart M, MacFarlane A, Sturgiss L, Mair F, Macdonald S, Smith S. What does Person Centred Care look like when the system doesn't work? *North American Primary Research Group Annual Scientific Meeting(NAPCRG)*. Phoenix, USA; November 2022 (Workshop)

McCallum M, Mair F, Macdonald S. Person Centred care: an untapped resource to increase patient capacity to manage multimorbidity in the context of poverty? *Society of Academic Primary Care (SAPC) Annual Scientific Meeting*. Brighton, UK; July 2023

McCallum M, Mair F, Macdonald S. Expanding Burden of Treatment Theory in the context of multimorbidity and poverty: the importance of community and biography. *Society of Academic Primary Care (SAPC) Annual Scientific Meeting*. Brighton, UK; July 2023 (Oral Presentation)

McCallum M, Mair F, Macdonald S. Making it work": How community groups create space for behaviour change. *Dutch Royal College of General Practitioner Annual Scientific meeting*. Groningen, Netherlands; September 2023 (Oral Presentation)

Definitions/Abbreviations

3D	3D Drumchapel (family support charity Drumchapel)
ABW	Asset Based Workshops
BOTT	Burden of Treatment Theory
BREWS	Pneumonic developed by Boehmer et al (2016) summarising the factors that influence capacity: Biography, Resources, Environment, Realisation of Work, Social functioning.
CHC	Cultural Health Capitol
CHW	Community Health worker (used as acronym in some of the articles found by the review)
COREQ	Consolidated Criteria for Reporting Qualitative Research – tool for Quality Appraisal of qualitative literature.
DCH	Drumchapel Cycle Hub
F/F	Family or Friends – abbreviation originally used in Sussman et al's (2016) appear
GP	General Practitioner
GC	Growchapel (community garden Drumchapel)
HIC	High Income Countries
LMIC	Low- and Middle-Income Countries
MeSH	Medical Subject Headings thesaurus: a controlled and hierarchically organised search terms produced by the National Library of Medicine.
MRC	Medical Research Council
MMS	Men Matter Scotland (male mental health support group Drumchapel)
LTCs	Long-term Conditions
RCT	Randomised Controlled Trial
RQ	Research Question
PCC	Person Centred Care
SED	Socioeconomic Deprivation
TB	Treatment Burden
UK	United Kingdom
WoS 20-07	West of Scotland Twenty-07 cohort

Chapter 1 Introduction to Thesis

1.1 Aim

This chapter presents the background to the thesis, describing the current literature on multimorbidity in the context of socioeconomic deprivation (SED), and why the construct of capacity is important. It then describes the motivation behind this work before presenting the thesis' aim and research questions.

1.2 Background

Multimorbidity (2 or more long-term conditions(LTCs)) is a key global health challenge, with limited evidence on optimal management (Skou et al., 2022). It is socially patterned, being more common, and beginning at an earlier age, in areas of high SED (Barnett et al., 2012). While work is urgently needed to improve management of multimorbidity in general, exploring the experience in the context of high SED is critical to ensure health services and interventions meet the needs of those requiring them most. Currently many health interventions widen existing health inequalities by being preferentially taken up in affluent populations (Berg et al., 2021).

As well as being associated with poor outcomes (Skou et al., 2022), managing multimorbidity generates significant work, the burden of which predominantly falls on those living with multimorbidity and their networks (Carl R. May et al., 2014). Burden of Treatment Theory (BOTT), the theory that underpins this thesis, terms this work to manage long-term conditions (LTCs) treatment burden. It proposes that where treatment burden outweighs capacity to carry work out, poorer outcomes occur (Carl R. May et al., 2014).

While treatment burden has been increasingly researched, the construct of capacity remains understudied (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022). Capacity is especially important in the context of multimorbidity and SED because factors likely to reduce capacity (poor transport access, low literacy) often cluster in areas of high SED (Carl R. May et al., 2014). Indeed, not accounting for capacity could be one reason why many current interventions are less effective in areas of high SED (Berg et al., 2021). In addition, in its current form BOTT is an individual based theory; the impact of wider community assets and experience remains unclear. Understanding capacity, and how community factors influence it in low-resource settings, could be key in designing interventions and services that reduce health inequalities.

1.3 Research Motivation

Recognising the importance of reflexivity, this section summarises the motivation for conducting this work. Sections discussing reflexivity will be written in the first person throughout the thesis.

I am an experienced GP, having always worked in areas of high SED. Therefore, I have witnessed the impact of early multimorbidity and the high prevalence of mental health comorbidity (often in patients with work and caring responsibilities). Promoting healthy behaviours and lifestyle change is a key part of LTC management. However, my patients often struggled to make changes or integrate self-management, due to factors out with their control. In addition, health was often not a priority because of other pressing social challenges.

Rarely did the wider health system give thought as to how lack of transport, poor literacy or early life experiences impacted on health or access to care. Supporting patients in resource poor settings results in extra work, unseen by the wider system (McCallum and MacDonald, 2021), with blame implicitly, and at times explicitly, applied to patients for “not engaging” in health services. This was at odds with my experience of people having to work hard, in very difficult circumstances, to try and meet health system requirements, with that work often unseen, or minimised.

My involvement in the GPs at the Deep End group (a GP advocacy group for GPs working in the 100 most deprived patient populations in Scotland) confirmed this unseen work and barriers were also seen by practitioners working in similar areas. This was further demonstrated in work I had undertaken exploring practitioner experience of caring for people living in areas of SED (McCallum and MacDonald, 2021).

Seeing daily the influence of social structures on the decisions people made about their health, I chose to pursue a career in academia hoping to contribute to the ongoing work seeking to improve health outcomes for the most vulnerable in society. I was able to spend two years as an academic fellow at Glasgow University gaining valuable research experience. The research questions in this PhD were informed by my desire to apply academic rigour to explore and understand the experience of managing multimorbidity in the context of high SED. This is with the aim that these findings could be built on to create applicable, practical, and authentic interventions and health care services that meet the needs of the patient populations I continue to work with.

1.4 Thesis Aim and Research Questions

The Aim of this thesis:

- To explore, and start to quantify, the influence of key factors impacting capacity to self-manage multimorbidity in the context of socio-economic deprivation, and how individual and community level factors interact to shape health management decisions.

The following four key Research Questions were developed:

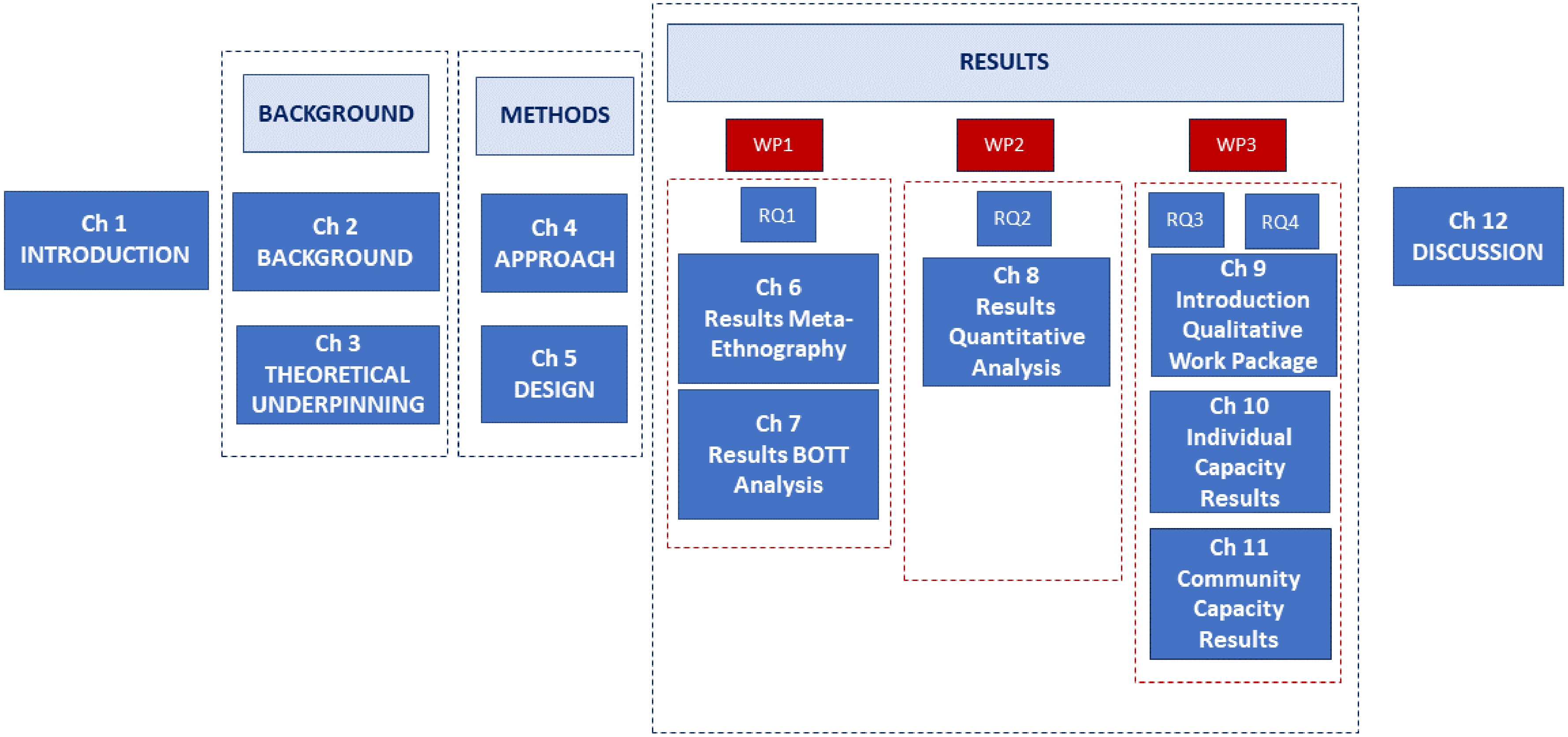
1. For current primary, or community, care multimorbidity interventions:
    a. Do they address self-management, treatment burden, patient capacity or socio-economic deprivation?
    b. What is the experience of participants, and what are the components of the interventions that they value or perceive to be of particular benefit??
2. What is the impact, if any, of individual or community factors on mortality, self-reported health, and healthcare utilisation?
3. What are the key factors that impact capacity to self-manage in those living with multimorbidity residing in areas of high socio-economic deprivation?

4. How do community beliefs and resources enhance, or limit, capacity at an individual level to manage multimorbidity?

1.5 Overview of Chapters

The Research Questions were answered using three work packages: a qualitative systematic review involving two analyses (meta-ethnography and BOTT analysis) (RQ1), a quantitative analysis of cohort data (RQ2) and qualitative analysis (taking an ethnographically informed approach in a community experiencing high SED (RQ3/4)). The outline of the thesis and how the different chapters relate to the research questions and the work packages is summarised in Figure 1.1.

Figure 1-1 Summary of Thesis Outline, demonstrating how the work packages relate to the research questions.



In conclusion, each chapter will present the following details:

- Chapter 2 describes the background literature in the context of multimorbidity and SED.
- Chapter 3 discusses BOTT and its applicability as the theoretical underpinning of this work.
- Chapters 4 discusses the methodological approach taken.
- Chapter 5 explores the rationale for the methods chosen.
- Chapters 6-11 display the results of the different work packages, situating them within the context of the wider literature where relevant:
    - Chapters 6 presents the findings of the systematic review meta-ethnography.
    - Chapter seven presents the systematic review BOTT analysis.
    - Chapter 8 presents the quantitative analysis results.
    - Chapter 9 describes the context of qualitative work and discusses the presentation of the qualitative results.
    - Chapter 10 summarises the findings in relation to Individual capacity factors.
    - Chapter 11 discusses the influence of wider community factors and describes a new construct “Community Capacity”.
- Chapter 12 discusses how findings from the three work packages impact each other, the strengths and limitations of this work, the implications and summarises the main conclusions reached.

Chapter 2 Background

2.1 Introduction

2.1.1 Aim

This chapter aims to summarise the key literature regarding health inequalities and multimorbidity, the background to this work.

2.1.2 Rationale

The overall aim of this thesis is to explore how individual and community factors coalesce to influence capacity to manage multimorbidity in the context of high SED. It focuses on multimorbidity, which is a significant global health challenge, but with limited evidence regarding management (Academy of Medical Sciences, 2019, Skou et al., 2022). Meanwhile, significant inequalities in health outcomes due to SED persist (Finch D, 2023), and this is particularly marked in multimorbidity, which is socially patterned (Barnett et al., 2012). Therefore, while there is an urgent need for high quality evidence in relation to multimorbidity management, this is particularly needed in the context of SED if existing inequalities are not to widen further.

This chapter seeks to contextualise this project by describing the current literature regarding wider health inequalities, before exploring the challenge of multimorbidity and how high SED impacts outcomes. It will also discuss the available evidence in this area. The aim of this chapter is not to provide an in-depth systematic review but to put the work of this thesis into context, indicating key papers that demonstrate where it fits within the wider literature base.

Of note most of the research in multimorbidity has been carried out in High Income Countries (HICs), prevalence and experience differs in low and middle income countries (LMIC)(Skou et al., 2022). As this work is in the context of a HIC the literature presented below, unless otherwise stated, is situated within that context.

2.2 Heath Inequalities – where are we now?

Disparities in health outcomes between the most affluent and most deprived in society have long existed (Black, 1980), and reducing this gap has been an aim of UK government policy since 1997 (Scottish Government, 2018). This has generated significant bodies of research and policy yet inequalities in health outcomes persist, and are even widening in some instances (Finch D, 2023, Marmot, 2020, Miall N, 2022).

The reasons for this persistence are complex and multifactorial. Ultimately, inequalities in health are driven by inequalities in wider society (Finch D, 2023, Marmot, 2020). Therefore, while important to (and this work does) explore what healthcare systems could do to improve outcomes, change is limited without action on the wider social determinants of health (Finch D, 2023). Furthermore, discourse around health inequalities may stigmatise the vulnerable populations it seeks to impact (Finch D, 2023, Kayleigh Garthwaite et al., 2016, Katherine E. Smith and Anderson, 2018). This has eroded already fragile trust, emphasising the need for future work that is co-produced and empowers communities (Finch D, 2023, Kayleigh Garthwaite et al., 2016). In addition, recommendations are not enough, significant “implementation gaps” exist (Finch D, 2023).

Despite clear evidence of the importance of upstream factors (e.g. stable housing, access to healthy food), initiatives often focus on easier to target downstream factors, such as health-related behaviours (K. Garthwaite and Bambra, 2017, Kayleigh Garthwaite et al., 2016, Mackenzie et al., 2016, Katherine E. Smith and Anderson, 2018). Residents of communities experiencing high SED understand how their experience of wider social circumstances leads to poor health (K. Garthwaite and Bambra, 2017, Katherine E. Smith and Anderson, 2018). However, they also internalise public health messaging about choice, subsequently blaming themselves, or “others” in their communities, for their poor health (Bourdieu et al., 2010, Mackenzie et al., 2016, Katherine E. Smith and Anderson, 2018).

The impact of SED is seen in healthcare utilisation with SED increasing likelihood of hospital admissions (Nishino et al., 2015, Payne et al., 2013, Warner et al., 2022). In addition, routine primary care encounters are also impacted; patients present with more problems, a higher proportion of which are psychological (McCallum and MacDonald, 2021, Stewart W. Mercer and Watt, 2007, O'Brien et al., 2011, O’Brien et al., 2014). Under-resourcing in practices working in areas of high SED (Fisher, 2021, McConnachie et al., 2023, Gary McLean et al., 2015, Stewart W. Mercer and Watt, 2007) produces consultations where GPs see more problems in less time, resulting in lower patient enablement and higher GP stress (Stewart W. Mercer and Watt, 2007).

2.3 Multimorbidity

Multimorbidity is one of the most significant challenges to global health systems; growing the evidence base in this area is a critical research priority (Academy of Medical Sciences, 2019, Skou et al., 2022). It is “the norm” in many HICs (Barnett et al., 2012, Bridget L. Ryan et al., 2018, Skou et al., 2022) with its prevalence rapidly growing in LMICs (Asogwa et al., 2022). In addition, longitudinal work in Scotland demonstrates its prevalence increasing over time: 59% of men born in 1950 had multimorbidity by age 60, compared to 37% born in 1930 (Katikireddi et al., 2017).

2.3.1 Definitions

While recognised as a critical problem, there is no universal definition of multimorbidity consistently used across the literature (Academy of Medical Sciences, 2019). The most common definition is the presence of two or more LTCs (Academy of Medical Sciences, 2019, Barnett et al., 2012). However, this wide definition creates a heterogenous group; the impact on daily life, and illness burden, of someone with eczema and high blood pressure will vary greatly from someone with stroke and depression. In addition, it does not account for disease severity, or the extra work generated when multimorbidity involves different body systems (for example the medications, and recommendations, for ischaemic heart disease and hypertension are similar, in contrast to those for depression and stroke).

This has led to a proliferation of other definitions (Lee et al., 2021, Stirland et al., 2020), and a call to identify factors that make multimorbidity *“complex”*. How to do this in practice remains unclear (Pati et al., 2023). Different definitions to capture complexity expand disease/medication counts, or involve weighted indexes, mandate LTCs are from different body systems, include only those with mental co-morbidities (recognising the significant impact on patient and practitioner experience (Stewart W Mercer et al., 2012, O'Brien et al., 2011, O'Brien et al., 2014, Payne et al., 2013) or include symptoms/risk factors (Aubert et al., 2020, Griffith et al., 2019, Harrison et al., 2014, Huntley et al., 2012, MacRae et al., 2023).

Despite the multiple options, disease (or medication count) remains the most utilised definition (Huntley et al., 2012, Lee et al., 2021). As would be expected, prevalence varies by the measure used (Griffith et al., 2019, MacRae et al., 2023), but there is little evidence that any of the more complex measures are better at predicting outcomes (such as mortality or healthcare utilisation) than disease count alone (Aubert et al., 2020, Huntley et al., 2012). Most of this work has been done on cross sectional data, therefore causal impact remains unclear. However, the few longitudinal studies conducted have been unable to show a more complex definition improves prediction accuracy (Ho et al., 2014, Kato et al., 2021, Pati et al., 2023, Vinjerui et al., 2020, Willadsen et al., 2018).

Given the plethora of options deciding on a definition seems daunting but as Skou et al (2022) summarise:

> *"at the patient (and household) level, having more than one condition, including a mental health disorder, translates into a higher health-care load and treatment burden, which is equally important to or more important than the precision in the 'technical' definition of multimorbidity"*

Therefore, given the wide use of disease count definitions, and limited evidence that more complex definition adds anything, the Academy of Medical Science (2019) definition (created after a comprehensive and systematic literature review) was chosen for this work:

> "The co-existence of two or more chronic conditions, each one of which is either:
>
> • A physical non-communicable disease of long duration, such as a cardiovascular disease or cancer.

- A mental health condition of long duration, such as a mood disorder or dementia.

- An infectious disease of long duration, such as HIV or hepatitis C.”

2.3.2 *Impact of Multimorbidity on Health Outcomes*

Multimorbidity is important because it complicates health care experience for both the patient and the practitioner, and has significant implications in terms of health outcomes and healthcare utilisation (Skou et al., 2022). Multimorbidity results in premature mortality (Jani et al., 2019, Menotti et al., 2001, Storeng et al., 2020, Vogeli et al., 2007). It also results in higher healthcare use (Lehnert et al., 2011) and, subsequently, higher healthcare costs (Lehnert et al., 2011, Marengoni et al., 2011, Vogeli et al., 2007). There is an increased risk of hospitalisation (Cassell et al., 2018, Payne et al., 2013, Vogeli et al., 2007), higher numbers of GP consultations (Cassell et al., 2018, Salisbury et al., 2011) and increased polypharmacy (Katie I. Gallacher et al., 2014, Townsend et al., 2003).

It increases the likelihood of disability and functional decline (Arokiasamy et al., 2015, Fried et al., 1999, Kato et al., 2021, Marengoni et al., 2011, Aine Ryan et al., 2015), has a negative impact on quality of life (Arokiasamy et al., 2015, Martin Fortin et al., 2004, Marengoni et al., 2011) and results in poorer self-reported health (Arokiasamy et al., 2015). It results in higher levels of loneliness (Scherer et al., 2016) and has negative impacts on occupation, and social activity (Pan et al., 2022, Pan et al., 2021, Vinjerui et al., 2020).

2.3.3 *A Significant Research Gap?*

Given the major impact of multimorbidity on the individual, and the wider health system, high quality evidence on how best to manage it is critical. However, despite increasing research in this area, including several well-funded RCTS (Stewart W. Mercer et al., 2016, Salisbury et al., 2018), the evidence for how best to improve quality of life for patients experiencing multimorbidity remains sparse (Susan M. Smith et al., 2021).

While high quality guidelines exist for multiple single conditions, there are few tackling multimorbidity (Guthrie et al., 2012, NICE, 2016). How to best manage multimorbidity and improve quality of life remains unclear (Academy of Medical Sciences, 2019, Skou et al., 2022, Susan M. Smith et al., 2021). Following single disease guidelines is not feasible and generates a great deal of work (Boyd et al., 2005, Guthrie et al., 2012, Skou et al., 2022, Tinetti et al., 2004). Importantly, the work associated with managing multimorbidity, borne primarily by the patient and their social networks, is a major burden (C. May et al., 2009, Carl R. May et al., 2014, Shippee et al., 2012). This is discussed in more detail in chapter 3, which explores Burden of Treatment Theory, the theoretical underpinning of this thesis.

It is unclear if there are clusters of morbidities that are particularly harmful, or specific pathways to develop multimorbidity (Academy of Medical Sciences, 2019, Skou et al., 2022). While complex, three broad contributing pathways to the development of multimorbidity are recognised: biological (ageing and inflammation), social (socioeconomic, behavioural, psychosocial) and medication (Skou et al., 2022). However, work to understand these pathways, including Artificial Intelligence, remain at an early stage (Pati et al., 2023, Skou et al., 2022). Therefore, there are significant evidence gaps in how to manage multimorbidity well.

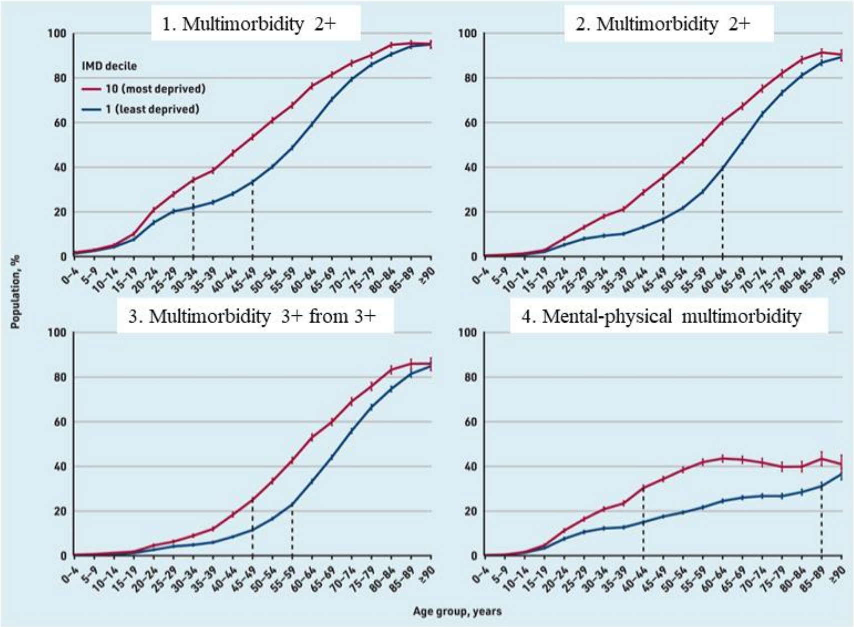
Recommendations, often reached by consensus of experts in the area, highlight the importance of care that is person centred, prioritising patient priorities, and seeking to minimise work for patients and their networks (C. May et al., 2009, NICE, 2016, Skou et al., 2022). However, there can be an inherent tension between patient priorities and preventing disease progression adding to the complexity in management for clinicians (McCallum and MacDonald, 2021, Skou et al., 2022).

2.4 Socioeconomic Deprivation and Multimorbidity

Multimorbidity is socially patterned; it is more prevalent in areas of high socioeconomic deprivation (Barnett et al., 2012, Cassell et al., 2018, Ingram et al., 2021, Jackson et al., 2015, Kivimäki et al., 2020, Mounce et al., 2018), where it begins on average 10-15 years earlier (Barnett et al., 2012). Furthermore, mental health co-morbidity is significantly increased in the context of SED (Barnett et al., 2012, Cassell et al., 2018, MacRae et al., 2023). Figure

2.1 demonstrates the impact different multimorbidity definitions have on prevalence by age and SED status and highlights both the increased prevalence and earlier diagnosis of mental health co-morbidity in high SED settings.

Figure 2-1 Figure demonstrating prevalence of multimorbidity using different multimorbidity definitions in the most and least deprived IMD decile by age. Graph 1 Multimorbidity defined as two or more conditions, Graph 2 Multimorbidity defined as three or more conditions, Graph 2 Multimorbidity defined as three or more conditions, Graph 3 Multimorbidity defined as 3 or more conditions from three body systems, Graph 4 Mental-Physical multimorbidity. Adapted from MacRae et al (2023)



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This higher burden of mental health co-morbidity is critical because mental health comorbidities increase treatment burden (O’Brien et al., 2014), increase complexity of management for practitioners (McCallum and MacDonald, 2021, O'Brien et al., 2011), hospitalisations (Frølich et al., 2019, Payne et al., 2013) and reduce patient enablement (Stewart W. Mercer and Watt, 2007).

Behavioural risk factors for chronic disease (including multimorbidity) also cluster in areas of high SED (Foster et al., 2018). However, this alone does not explain differences in multimorbidity prevalence (Katikireddi et al., 2017); SED has an independent impact on outcomes independent of health behaviours (Foster et al., 2018, Katikireddi et al., 2017).

2.4.1 Evidence in this context

A Cochrane review examining evidence of efficacy of multimorbidity interventions identified only 17 RCTs (Susan M. Smith et al., 2021), a small evidence base for such a key problem. It found interventions had some efficacy improving mental health outcomes, but little impact on clinical outcomes (Susan M. Smith et al., 2021). Interventions had limited effect on quality of life scores, or on self-efficacy, with little data available to assess cost-effectiveness (Susan M. Smith et al., 2021).

Despite the clear association between multimorbidity and SED only one included pilot study directly targeted this, Care PLUS (Stewart W. Mercer et al., 2016). It took a whole system approach resourcing GPs to provide continuity of care and extra consultation time for patients with multimorbidity living in areas with SED (Stewart W. Mercer et al., 2016). It improved well-being and was found to be cost-effective (Stewart W. Mercer et al., 2016).

Due to the complex role of SED on health outcomes, including multimorbidity, social prescribing has been suggested as a promising intervention (Fisher, 2021). Unfortunately, while links workers (social prescribers who aim to support social problems impacting on health) have been rolled out across the UK, they are disproportionately located in practices serving affluent areas, potentially further widening inequalities (Fisher, 2021, Fisher et al., 2023). Furthermore, despite multiple social prescribing programmes, evidence for efficacy is lacking (Bickerdike et al., 2017, Bridget Kiely et al., 2022). This is partly due to programme heterogeneity, and lack of robust evaluation of current initiatives (Bickerdike et al., 2017). Work is planned in this area, including an RCT targeting social prescribing in patients with multimorbidity in areas of high SED (B. Kiely et al., 2021).

2.5 Conclusion

This chapter summarises the relevant background literature regarding multimorbidity and high SED. It demonstrates the significant impact of multimorbidity, as well as the paucity of evidence for optimal management. It highlights the pervasive issue of health inequalities, and the impact high SED has on experience and management of multimorbidity. Understanding what influences how people manage multimorbidity is critical to inform health service design, particularly in areas of high SED. This work sought to evidence this important knowledge gap by applying Burden of Treatment Theory in this context. This theory, and why it was chosen, is discussed in the next chapter.

Chapter 3 Theoretical Background

3.1 Introduction

3.1.1 Aims

This chapter will describe Burden of Treatment Theory (BOTT), the theoretical underpinning of this work and how it relates to the overall aim of this thesis.

3.1.2 Rationale

This thesis explores how capacity (a BOTT construct) influences management of multimorbidity in the context of SED. BOTT is a relatively new theoretical framework (Carl R. May et al., 2014), that has been applied in different health contexts (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022), and even in the context of domestic violence (Tarzia et al., 2016). It has two main constructs: treatment burden (TB), which has been more extensively studied, and capacity which is relatively unexplored (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022).

This thesis is underpinned by BOTT, and examines capacity, one of its constructs, in-depth. BOTT informed the aim, methodological approach, and interpretation of the results of this work. This chapter describes the development of BOTT including its application in research settings. It will not present an exhaustive summary, rather it will describe the underlying constructs and why it was selected for this work.

3.2 The role of theory

“A theory is simply a system of ideas or concepts intended to explain something.”

p.21(Pope and Mays, 2020)

Theory is important in the context of qualitative research where its use is shaped by ontological and epistemological stance (discussed in detail in Chapter 4). Use of theory can increase rigour and applicability, and help situate work more clearly within an existing literature base (Pope and Mays, 2020).

Theoretical approaches can be inductive (arising from the data), deductive (applying existing theory to the data) or abductive (a combination), all of which can expand knowledge and understanding (Giacomni, 2010, Green and Thorogood, 2018, Pope and Mays, 2020). Theory can inform decisions regarding methodologies, or interpretation of results.

3.3 Burden of Treatment Theory

Burden of Treatment Theory is a *"model for the relationship between sick people, their social networks and healthcare services"* (Carl R. May et al., 2014). It allows exploration of the interaction between multiple factors influencing patient's capacity to carry out the work associated with long-term conditions (LTCs). It provides a framework demonstrating how wider factors influence outcomes through understanding their impact on both capacity and TB. These impacts are not universal, with certain populations disproportionately affected by unequal opportunity (Carl R. May et al., 2014).

3.3.1 The Development of Burden of Treatment Theory

3.3.1.1 The patient experience of illness

Technological, and medical, advances have changed the experience of illness, challenging health systems to adapt from primarily managing acute, often infectious, single-system disease to multiple LTCs (Academy of Medical Sciences, 2019, Barnett et al., 2012). This has shifted health service delivery, moving more care to the community, often changing health professionals' roles (Carl R. May et al., 2014). Crucially, much of the increasingly complex work required to manage LTCs is now delegated to patients, which can be overwhelming (C. May et al., 2009, Carl R. May et al., 2014, Shippee et al., 2012).

Living with LTCs is often negative, with significant burden from symptoms, biographical disruption (where sense of identity, or purpose, is impacted by a diagnosis of a LTC), and damaging impacts on family and social life (Bury, 1982, Juliet Corbin and Strauss, 1985, Cornwell, 1984). Corbin and Strauss' seminal work "Managing Chronic Illness" first highlighted the significant burden the work of chronic illness created (Juliet Corbin and Strauss, 1985). They recognised three types of work:

- Illness: work required to manage illness

- Everyday: organisation and co-ordination of various types of work necessary to operationalize any plans of action

- Biographical: work required in defining and making identity

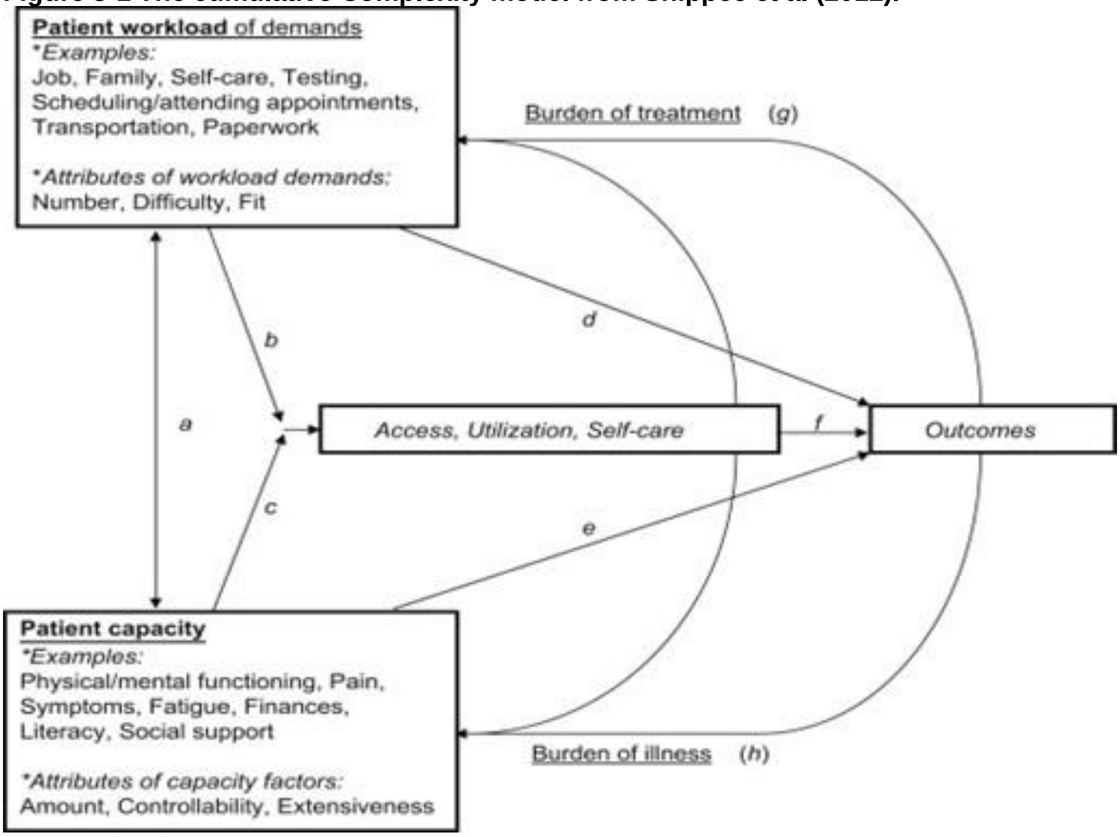
(Juliet Corbin and Strauss, 1985)

Balancing these different types of work resulted in “unending work” (Juliet M Corbin and Strauss, 1988), experienced not just by patients but their spouse, and wider networks (Juliet M Corbin and Strauss, 1988).

3.3.1.2 The Development of the Cumulative Complexity Model

Shippee et al (2012) built on these understandings of work, and the potential for patients to be overwhelmed, to create the cumulative complexity model (fig 3.1).

Figure 3-1 The cumulative Complexity model from Shippee et al (2012).



It proposes patients with LTCs accumulate complexity over time; that complexity is increased when patients are overwhelmed. This model demonstrates how multiple factors influence both patient work (TB) and the capacity to do that work. It emphasises the need to consider both capacity and burden, and the interaction between the two over time, to understand long-term impacts on health outcomes (Shippee et al., 2012). It also highlights how the negative feedback loops of Burden of Illness and Treatment further reduce capacity and increase work. Finally, this conceptual model provides a lens to understand why some populations experience poorer outcomes by exploring how gender, ethnicity and socioeconomic status may impact on the underlying constructs of work and capacity.

3.3.1.3 Social Networks

The exact role of networks in the context of LTCs, and their influence on health outcomes, remains unclear – particularly because they are hard to define and measure (Rogers et al., 2015). Multinational studies suggest networks with larger numbers of people improve self-management, particularly if people within them actively engage in illness work (Reeves et al., 2014, Ivaylo Vassilev et al., 2016). The impact of networks on wellbeing remains less clear (Reeves et al., 2014, Ivaylo Vassilev et al., 2016). Involvement in wider community networks may have a positive effect on outcomes (Koetsenruijter et al., 2016, Reeves et al., 2014). Active contribution to networks, and not just being “helped”, also has a positive influence (Reeves et al., 2014).

3.3.2 Burden of Treatment Theory Constructs

May et al (2014) built on the cumulative complexity model, work on social networks and Normalisation Process Theory (which allows categorisation of different types of work) (NPT, 2021) to develop Burden of Treatment Theory summarised in Figure 3.2. The overarching constructs of capacity and TB are further broken down into sub-constructs described in detail in table 3.1.

Figure 3-2 Summary of key Burden of Treatment Theory constructs adapted from May et al (2014)

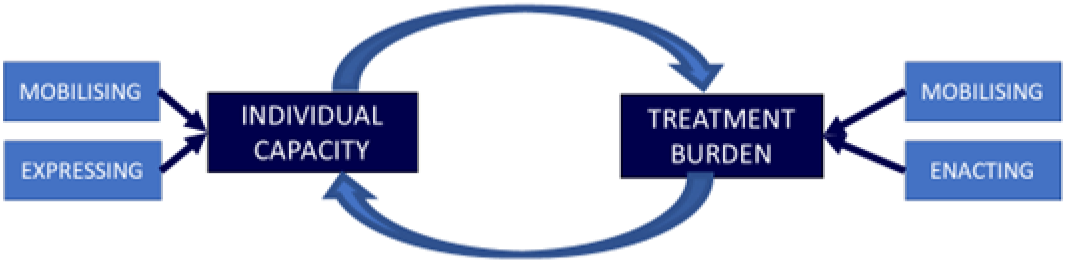


Table 3-1 Summary of key constructs of Burden of Treatment Theory adapted from Chikumba et al, (2022)

Constructs	
1: Mobilising capacity	**Capacity of individuals and their relational networks to interact and utilize healthcare services**
1.1: Agency	Things done to engage with health problems and with others: impact of physical/psychological/sensory aspects of disease and disability; material and cognitive resources at their disposal
1.2: Relationality	Social networks through which agency can be expressed and distributed: intensity, size, and complexity of relational networks. Will include health professionals
S 1.3: Opportunity	Availability of services.
1.4: Control over service	What organisations do to determine content, structure, and resources of services.
2: Expressing capacity	**The qualities patients and their relational networks need to possess if they are to exploit healthcare opportunities**
2.1: Social Skill	Skills necessary to engage and mobilise cooperation of others, to negotiate controls placed on resources to help with the tasks of care.
2.2: Functional Performance	Degree to which people possess cognitive and material capacity to meet demands.
2.3: Structural resilience	How patient’s network of support can be used to absorb, compensate, and even thrive when things change.
2.4: Social Capital *(Of note definition different from its wider use in sociology)*	How patient’s social network can be used for gaining information and resources that help with care.
3: Treatment Burden (Mobilising)	**Understanding work and mobilising resources required**
3.1: Sense Making (coherence)	The way sick people and their social networks identify, understand, and explain the diverse tasks that make up work, internalize these and plan for their requirements
3.2: Building and maintaining relational networks (cognitive participation)	How patients and their networks enrol, engage, and maintain contacts in their support network.
3.3: Enacting delegated work (collective action)	How patients and their networks allocate and execute specific tasks, negotiate accountability for outcomes and organise and realise the mobilisation of resources

3.3.1: Material and cognitive practices to be done (interactional workability)	Whether tasks are perceived to be workable, and how patient and carers navigate their different responsibilities.
3.3.2: Practical Help (skill set workability)	Having or obtaining the practical skills to carry out multimorbidity work
3.3.3: Exploitable resources (contextual integration)	Having or obtaining the resources to carry out work required by multimorbidity.
3.3.4: Confidence in outcomes (relational integration)	Factors that influenced whether patients have confidence in the outcomes of delegated tasks.
4. Treatment Burden (Enacting)	**Monitoring and adapting work as required**
4.4: Reflexive monitoring	Collecting information regarding sign and symptoms and views of significant others, undertake individual and collective appraisal and apply it to the reconfiguration of work

3.3.2.1 Treatment Burden

TB has two sub-constructs: mobilising and enacting delegated tasks (Carl R. May et al., 2014). Mobilising delegated tasks uses the constructs of normalisation process theory to understand patient work (NPT, 2021). Normalisation process theory allows categorising of the different types of work required to embed work into daily practice (Carl R. May et al., 2014, NPT, 2021). Enacting delegated tasks explores the factors that influence how that work is then carried out and done.

3.3.2.2 Capacity

Capacity also has two subconstructs (mobilising and expressing) and each sub-construct has categories within it. Mobilising capacity factors summarise resource that people have access to, including the resource from the wider health system and how it provides services. Expressing factors are those that influence whether people can utilise that resource.

3.4 Applications of Burden of Treatment Theory

3.4.1 Treatment Burden(TB) and Capacity

The construct of TB has been increasingly researched, enabling a deeper understanding of contributors to burden and the role of wider structural issues (Adam et al., 2023, K. Gallacher et al., 2011, Adem Sav et al., 2017, Tran et al., 2015). This has resulted in the development of several measures (Polly Duncan et al., 2020, Eton et al., 2020, Tran et al., 2014) which have demonstrated high levels of TB in the context of LTCs (A. Sav et al., 2016, Tran et al., 2020).

In contrast, capacity has been relatively under-researched with no measures developed and limited understanding of the key factors that influence it (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022). There is copious research on individual factors that may influence capacity (e.g. health literacy, transport, social networks (Carl R. May et al., 2014, McKinlay et al., 2017, Reeves et al., 2014, Rogers et al., 2015, Shippee et al., 2012, Ivaylo Vassilev et al., 2013, Ivaylo Vassilev et al., 2016, Ivaylo Vassilev et al., 2011) but the interaction between these factors is less well understood.

A qualitative systematic review exploring capacity recognised it is a *"complex and dynamic concept, exceeding resources alone"* (Kasey R. Boehmer et al., 2016). It identified five areas (summarised by the acronym BREWS) influencing capacity in the context of health care:

- **B**iography: LTCs require work to reframe biography in this context. The extent people manage to incorporate their diagnosis into their biography influences underlying capacity.

- **R**esources: Access to, and ability to mobilise, resources

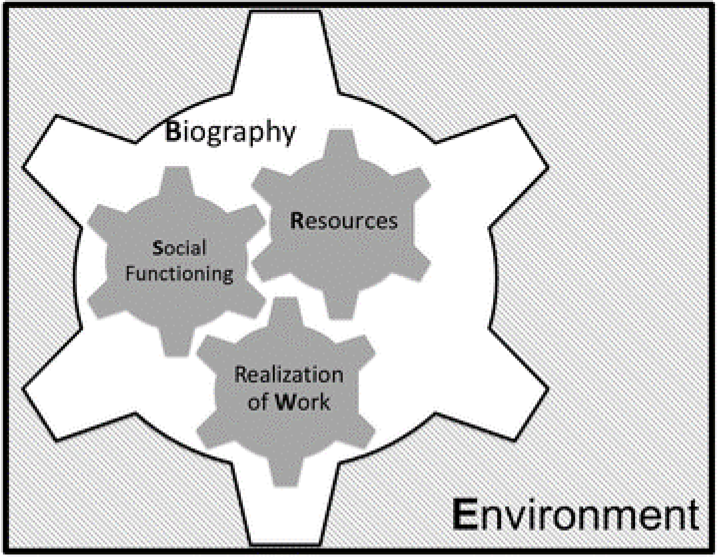
- **E**nvironment: wider environment influences capacity

- **W**ork: completing the work (and in the process learning new skills) can grow capacity

- **S**ocial networks: supportive, or potentially negative, impact of social networks

How these conceptually interact together as a model to influence individual capacity is summarised in figure 3.3:

Figure 3-3 The BREWS model Boehmer et al (2016)



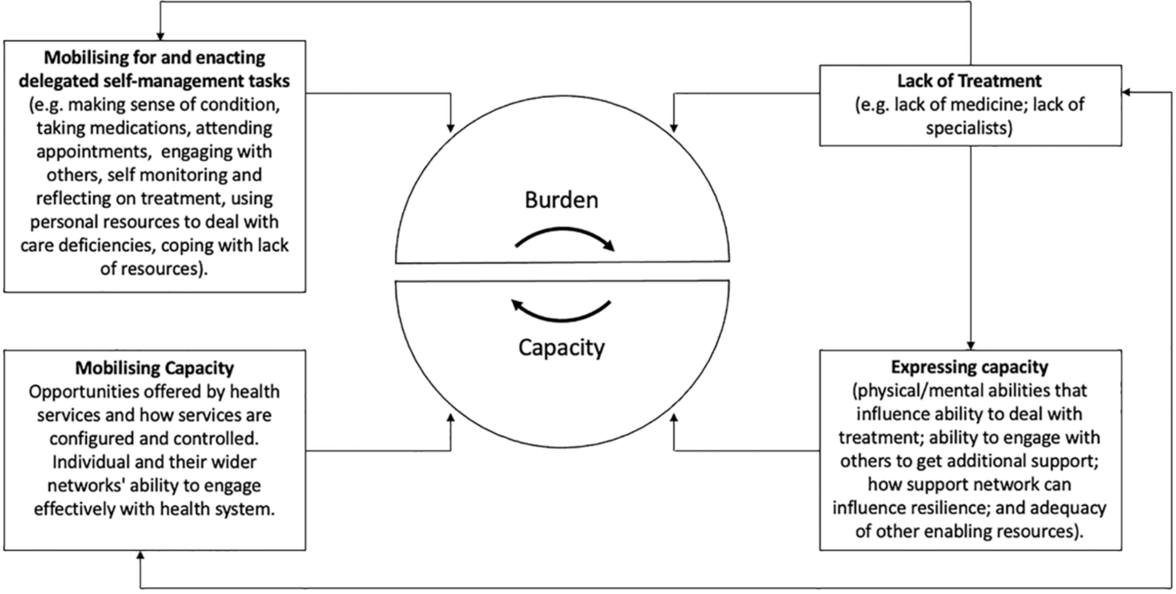
A strength of the BREWS model is it situates capacity factors within the context of wider environment and recognises the foundational importance of biography. However, an important critique is that the categories are large and vague, in contrast to the clearly defined constructs within BOTT, making it less easily applicable.

3.4.2 Burden of Treatment Theory in different contexts

In the meantime BOTT in its entirety has been applied in several contexts: stroke (K. Gallacher et al., 2011, Katie Gallacher et al., 2013b, Kyle et al., 2020), heart failure (K. Gallacher et al., 2011), cancer (Adam et al., 2023), and multimorbidity in Low and Middle Income Countries (LMIC)(Chikumbu et al., 2022, Mbokazi et al., 2023, van Pinxteren et al., 2023a, van Pinxteren et al., 2023b). It has also been used in a domestic violence setting (Tarzia et al., 2016).

It has been broadly applicable in all these contexts, with recognition that there may be specific factors unique to single diseases. The work in LMIC settings, all exploring multimorbidity, suggests BOTT may require expansion in these settings. Similar to BREWS (Kasey R. Boehmer et al., 2016), Chikumbu et al(2022) recognised the importance of the biographical work of “coming to terms” with multimorbidity. They also identified the importance of community based social support and identified that lack of treatment was a specific burden in this context (their suggested expansion of BOTT is demonstrated in Figure 3.4).

Figure 3-4 Figure demonstrating how BOTT constructs applied in an LMIC resource poor setting, highlight the significance of lack of treatment (Chikumbu et al, 2022)



Van Pinxteren et al (2023a), in a similar setting, identified cyclical precariousness as a separate wider community factor independently impacting both capacity and TB, which required to be accommodated in the use of BOTT in this context (van Pinxteren et al., 2023a).

Other work conducted in South Africa highlighted how people living with multimorbidity in resource poor settings embraced “ubuntu”; *“a Pan-African philosophy that promotes a communal identity and expresses compassion, reciprocity, dignity, harmony, and humanity”* (Mbokazi et al., 2023). This embedded community level experience influenced how social networks in this context shared and supported one another. It allowed people to share their treatment burden and enhanced underlying capacity. They highlight the importance of community level factors in how people manage multimorbidity, and suggest incorporating ubuntu into BOTT in this context (Mbokazi et al., 2023).

3.4.3 Relevance of Burden of Treatment Theory for this work

Chapter two highlighted the considerable body of work regarding health inequalities, and how, despite significant investment, poor outcomes persist, particularly in the context of multimorbidity. Multimorbidity increases TB and reduces capacity (Boyd et al., 2005, Guthrie et al., 2012, C. May et al., 2009, Carl R. May et al., 2014, O'Brien et al., 2014, Shippee et al., 2012, Skou et al., 2022, Tinetti et al., 2004).

In this context, BOTT, especially the capacity construct, provides potential mechanisms to explain why health inequalities persist. Under-researched, capacity is rarely explicitly considered in daily clinical practice (C. May et al., 2009). Factors that negatively impact capacity (e.g. health literacy, transport and social networks) (Carl R. May et al., 2014, McKinlay et al., 2017, Reeves et al., 2014, Rogers et al., 2015, Shippee et al., 2012, Ivaylo Vassilev et al., 2013, Ivaylo Vassilev et al., 2016, Ivaylo Vassilev et al., 2011) cluster in areas of high SED. Not considering or supporting wider capacity factors could be one reason why many health interventions widen rather than narrow existing outcome gaps. A deeper understanding of capacity, and what enhances it, could provide critical targets for future interventions in multimorbidity that may narrow health inequalities.

In addition, the impact of wider community factors on individual capacity remains unclear. Work in LMIC settings demonstrated the importance of wider community factors such as precarity, ubuntu and lack of treatment on both capacity and TB (Chikumbu et al., 2022, Mbokazi et al., 2023, van Pinxteren et al., 2023a). BOTT primarily operates at the level of the individual and their social networks. Expression of capacity contains the subconstructs of structural resilience (how social networks support absorb, or compensate for, change) and social capital (how social networks gain information and resources that help with care). The focus, however, is on how individuals and social networks access and utilise community resource. Mobilising Capacity includes the subconstructs of opportunity (availability of services) and Control (what organisations do to determine content, structure, and resources of services) but does not consider wider factors (out with the health system's control) that may influence how people access services. Therefore, at present it does not consider whether wider community experiences may have a separate influence on capacity.

Taking a wider community-based approach has been advocated as a more beneficial way of targeting socially vulnerable populations. (Kayleigh Garthwaite et al., 2016, Katherine E. Smith and Anderson, 2018, Ivaylo Vassilev et al., 2013). Furthermore, exploring communities with an asset, rather than deficit, based approach is empowering and could be important in reducing stigma in vulnerable communities (Kayleigh Garthwaite et al., 2016).

Therefore, capacity (and particularly the influence of wider community factors) was identified as an important, under-researched construct that could be critical in future work to mitigate inequalities. BOTT underpins this thesis as it provides a framework for the exploration of capacity, particularly in the context of multimorbidity and SED. However, due to the scarcity of work in this area, a purely deductive approach was not taken. This thesis sought to both understand the applicability of BOTT in this context and to explore other emerging individual and community factors that influence capacity to manage multimorbidity in the context of high SED. The overarching aim of this thesis is:

- To explore, and start to quantify, the influence of key factors impacting capacity to self-manage multimorbidity in the context of socio-economic deprivation, and how individual and community level factors interact to shape health management decisions.

It sought to do this by answering the following Research Questions:

1. For current primary, or community, care multimorbidity interventions:
    a. Do they address self-management, treatment burden, patient capacity or socio-economic deprivation?
    b. What is the experience of participants, and what are the components of the interventions that they value or perceive to be of particular benefit?

2. What is the impact, if any, of individual or community factors on mortality, self-reported health, and healthcare utilisation?

3. What are the key factors that impact capacity to self-manage in people with multimorbidity living in areas of high socio-economic deprivation?

4. How do community beliefs and resources enhance, or limit, capacity at an individual level to manage multimorbidity?

3.5 Conclusion

In conclusion, this chapter has summarised the main BOTT constructs, and highlighted the paucity of work in our understanding of capacity. While BOTT focuses primarily on healthcare provision and on individuals and their social networks, application in resource poor settings has identified the importance of wider community factors on both treatment burden and capacity (Mbokazi et al., 2023, van Pinxteren et al., 2023a). A greater understanding of capacity, and how to enhance it, may be critical to design services that narrow rather than widen existing health inequalities. Therefore, this work sought to explore in depth the individual and community level factors that influence capacity to manage multimorbidity in the context of high SED. The results of which could inform more equitable health service, and intervention, design in the future.

Chapter 4 Methodological Approach

4.1 Introduction

4.1.1 Aim

The aim of this chapter is to discuss the methodological approach to this work, and why a multi-method approach was taken.

4.1.2 Rationale

All research is shaped by the underlying worldviews and assumptions of the researchers, whether they are explicit in stating these or not (Green and Thorogood, 2018). Therefore, it is important that these underlying stances are clarified, to allow adequate understanding, and appropriate critique, of study design, and results.

This chapter will briefly outline the main epistemological and ontological traditions before exploring mixed method research. It will then discuss the epistemological and ontological stances used in mixed method approaches, before discussing the stance taken in this thesis.

The chapter will then describe the subtle difference between mixed and multi-method approaches, and why a multi-method approach was judged to be the most appropriate for this work. Considerations regarding theory in the approach chosen, and how BOTT was used in the design and analysis of this work are also discussed. Finally, the chapter will explore the importance of reflexivity in the context of this work.

4.2 Epistemology and ontology

There are significant differences in the theoretical paradigms that underpin different research studies, and disciplines (Lincoln and Guba, 2017). These different ontologies (beliefs about reality) and epistemologies (beliefs, dependent on underlying ontology, about how to obtain knowledge) ultimately influence how a researcher approaches their work and shapes the research questions asked and the methodologies chosen.

Ontology is often thought of as a spectrum, with opposing paradigms on how to view reality at either end. Realism proposes a “stable reality” (Green and Thorogood, 2018), both in the natural and social world, that is separate and independent (Giacomni, 2010, Green and Thorogood, 2018, Lincoln and Guba, 2017). Realism leads to a positivist (or post-positivist) epistemology that purports that these real facts can be objectively observed or measured in a rational way, where the researcher seeks to be a neutral value-free observer (Giacomni, 2010, Green and Thorogood, 2018, Lincoln and Guba, 2017).

At the other extreme is the ontology of relativism which views reality as entirely socially constructed (Giacomni, 2010, Green and Thorogood, 2018, Hammersley, 1992, Lincoln and Guba, 2017). This stance claims reality is not empirically measurable, accessible only through ideas and perceptions, with no hierarchy of knowledge where one thing is more “true” than another (Giacomni, 2010, Green and Thorogood, 2018). With relativism as an underlying ontology the epistemology of interpretivism seeks to understand this “world of ideas” (Giacomni, 2010) by interpreting and exploring shared meaning and experience. In this context the researcher cannot separate themselves from their subjects, or be objective (Giacomni, 2010, Green and Thorogood, 2018). As they interpret the social world they observe, they suppose that research participants are similarly interpreting, making decisions that are based on the meanings derived from their environments (Rock, 2001). Within an established community this process also occurs, at a community level, with shared meaning in turn influencing actions (Rock, 2001).

In contrast to positivism, the researcher seeks to understand, and is more interested in, the interpretation of reality rather than reality itself (because an objective independent reality does not exist) (Giacomni, 2010). In a similar vein, social constructivism, also rooted in relativism, seeks to understand the process by which people construct reality (Giacomni, 2010, Rock, 2001), and in particular the communal experience of developing shared meanings within communities. Within both these paradigms “reality” is not accessible to the researcher. Researchers only have access to their own ideas and constructs, which in turn are based on participants constructs (Giacomni, 2010). As Geertz (2017) summarises: *“What we call our data are really our own constructions of other people’s construction of what they and their compatriots are up to”*.

Interpretivist enquiry involves a consistently evolving approach as data emerges and pre-suppositions are questioned (Hammersley, 1992, Rock, 2001). This is an interactive creative process (Rock, 2001), where new lines of enquiry, and important questions, emerge in the field itself (Rock, 2001). Knowledge will only emerge later in the process, in contrast to the positivist deductive mindset (Green and Thorogood, 2018, Rock, 2001).

Finally, there is growing awareness that many of our recognised narratives regarding reality are influenced by an uncritical acceptance of the prevailing structures and norms of society over time. Critical and postmodern approaches take an intentionally critical as well as interpretative approach to research (Giacomni, 2010, Green and Thorogood, 2018). They directly challenge the interpretivist assumption that all views are equal by applying a critical activist lens to their research, such as feminist enquiry (Giacomni, 2010, Green and Thorogood, 2018).

Underlying epistemological and ontological assumptions guide the methodologies chosen. Qualitative methodology is traditionally used with interpretivist or constructivist epistemologies which are usually seen as inductive (knowledge arising rather than being derived from the data). Positivism is more likely to use quantitative methodology, using deductive methodology to test pre-existing hypotheses.

However, while clarifying theoretical assumptions is important, it should be noted that often the research questions, rather than epistemology, drive the methods chosen (Giacomni, 2010, Green and Thorogood, 2018). There is growing awareness in health services research that as questions are often complex they require multiple types of knowledge to answer fully (Bunce et al., 2014, Edward A S Duncan and Nicol, 2004, Giacomni, 2010, Eileen Murphy et al., 1998, Skivington et al., 2021). Working across boundaries can cause tension, but using an array of knowledge obtained from different methodologies can provide robust, and rich answers (Andrew et al., 2009, Edward A S Duncan and Nicol, 2004, Giacomni, 2010, Green and Thorogood, 2018, Eileen Murphy et al., 1998, Yardley and Bishop, 2015).

4.3 Mixed methods in Health Research

Mixed methods research has significantly increased in the health research field in recent years (Andrew et al., 2009, Anguera et al., 2018, Doyle et al., 2016). The interest in the potential for mixed methods has been driven by both researchers and funders (Andrew et al., 2009, Eileen Murphy et al., 1998, Yardley and Bishop, 2015). Mixed methods work can draw on strengths from different methodologies, compensating for weaknesses of one method alone (Andrew et al., 2009, Anguera et al., 2018, Doyle et al., 2016, Shorten and Smith, 2017). They can promote greater integration of the patient voice, and may provide deeper, more complete answers to research questions (Anguera et al., 2018, Creswell, 2014, Shorten and Smith, 2017). Doyle et al (2016) describe the appeal of mixed methods as *“largely grounded in its ability to offer a broader and deeper understanding of complex health circumstances and human phenomena”*. However, mixing methods raises important epistemological, ontological, and methodological concerns. While this section will argue the value of mixed methods research, like all approaches the underlying assumptions, and appropriateness must be examined.

4.3.1 Philosophical basis

The epistemologies and ontologies that underly different methodologies are at odds with one another, and those with strong convictions of interpretivism, and positivism would (and do) contend these contrasting paradigms, and therefore the methods associated with them, cannot be mixed (Andrew et al., 2009, Bishop, 2015, Doyle et al., 2016, Shannon-Baker, 2016, Yardley and Bishop, 2015). This has generated significant discussion amongst researchers who have wrestled with whether, and if so how, different methodologies could be mixed (Andrew et al., 2009, Doyle et al., 2016, Shorten and Smith, 2017, Yardley and Bishop, 2015).

While positivism and interpretivism represent two extremes, many researchers find themselves straddling the two, and the approach taken is often led by research questions rather than underlying ontology. Indeed, holding radical perspectives on either side raises important questions. A radical interpretivist view is untenable living in a world ruled by natural immutable laws such as gravity; in contrast given the researcher chooses research questions and design, even the most committed positivist, while striving to reduce bias as much as possible, must recognise that they cannot claim to be completely independent of the work they conduct.

Whether you can frame mixed methods work within a coherent epistemological and ontological paradigm has been discussed widely (Andrew et al., 2009, Anguera et al., 2018, Bishop, 2015, Doyle et al., 2016, Mertens and Hesse-Biber, 2013, Eileen Murphy et al., 1998, Shannon-Baker, 2016, Yardley and Bishop, 2015). Indeed, with the rise of mixed methods work the need to ensure high quality and rigour in conducting, and appropriate guidance for appraising, this work is more critical than ever (Doyle et al., 2016, Eileen Murphy et al., 1998). While there are no current guidelines for researchers, Table 4.1 summarises some of the common stances that researchers adopt in this area.

Table 4-1 Table summarising the main philosophical stances adopted by mixed method researchers.

Stance	Description
Pragmatism (Andrew et al., 2009, Bishop, 2015, Doyle et al., 2016, Mertens and Hesse-Biber, 2013, Shannon-Baker, 2016, Yardley and Bishop, 2015, Yvonne Feilzer, 2010)	Most common stance taken by mixed method researchers; focuses primarily on the outcome, and any practical solutions resulting from the findings. Pragmatist approaches centre on the usefulness of findings; the research question is key, not whether findings reflect reality. Recognises the different epistemologies of quantitative and qualitative work, but *"pragmatism breaks down the positivist and constructivist ways of knowing in order to look at what is meaningful from both"* (Shannon-Baker, 2016). Critics raise concerns about who decides what work is useful, and an overly simplistic application of this paradigm (Mertens and Hesse-Biber, 2013)
Realist stances (Andrew et al., 2009, Doyle et al., 2016, Edward A S Duncan and Nicol, 2004, Giacomni, 2010, Hammersley, 1992, Rock, 2001, Shannon-Baker, 2016)	Realist stances mix the constructivist stance (the experience of reality being socially constructed) with an ontological perspective of an objective reality. In recent years several different realist stances have been developed. Critical realists aim to measure/understand phenomena but recognise when reporting results are an approximation of the true reality (Shannon-Baker, 2016). Context, and understanding underlying causes and mechanisms is critical. Subtle realism recognises phenomena do operate independently of our ideas (there is an independent reality) but that many phenomena cannot be directly measured or accessed other than through ideas. It is discussed in more detail below.
Transformatic emancipation (Shannon-Baker, 2016)	This approach prioritises focusing on, and empowering, marginalised groups, amplifying their voices. It requires strong community relationships.
Dialectics (Mertens and Hesse-Biber, 2013, Shannon-Baker, 2016)	Proponents of this approach argue two research paradigms can be used together. Rather than integrating the approach findings the tension between stances is highlighted. This tension is used in the interpretation of results, valuing different or divergent results.

This thesis has chosen to adopt a stance of subtle realism. First described by Hammersley (1992), it recognises that phenomena operate independently of ideas (there is an independent reality) but that many phenomena cannot be directly measured or accessed other than through ideas (Giacomni, 2010, Hammersley, 1992, Eileen Murphy et al., 1998, Rock, 2001). Research involves subjective perceptions and observations, so different methods will produce different perspectives, all of which are true (Edward A S Duncan and Nicol, 2004, Giacomni, 2010, Hammersley, 1992, Eileen Murphy et al., 1998, Rock, 2001). Thus:

> *"there can be multiple, non-contradictory and valid descriptions and explanations of the same phenomenon"* (Hammersley, 1992)p51

Unlike social constructivism, truth is not measured by consensus (Eileen Murphy et al., 1998): disagreement is expected when exploring multiple individual perceptions, and plausibility is important in interpretation (Hammersley, 1992, Eileen Murphy et al., 1998). As an interpretative form of enquiry, subtle realism recognises the central role of the researcher, who cannot be independent of the process, and whose presence will inevitably influence the field they study (Edward A S Duncan and Nicol, 2004, Giacomni, 2010, Hammersley, 1992, Eileen Murphy et al., 1998, Rock, 2001). Therefore, reflexivity (discussed in detail below) is important at every stage of the work.

Research therefore aims to create constructs that reflect rather than represent reality (Edward A S Duncan and Nicol, 2004, Hammersley, 1992, Eileen Murphy et al., 1998, Rock, 2001). The researcher cannot claim to have absolute certainty regarding their work (Edward A S Duncan and Nicol, 2004, Hammersley, 1992, Eileen Murphy et al., 1998), but where work is rigorously conducted, they could be reasonably confident in the findings they present.

This means that a subtle realism stance is compatible with multiple approaches and methods being used. The choice of method is related to the research questions asked. Subtle realism has been recognised as a valid stance for health researchers in multiple disciplines, as well as funders, to take (Edward A S Duncan and Nicol, 2004, Eileen Murphy et al., 1998).

As well as a philosophical underpinning, the appropriateness of a mixed methods approach should be assessed by reflecting on the justification for the adoption of different methods. One of the marks of quality in appraising the appropriateness of a mixed method approach is whether, and how, the choice to use mixed methods adds value to any given study (Bryman, 2007, Doyle et al., 2016). Reflecting on this question may address the legitimate concerns surrounding the justification for a mixed method approach.

4.3.2 Mixed or multi methods?

A further issue within the fast-growing field of mixed methods research has been the lack of agreed definitions; the phrase mixed methods is used to describe multiple study types. It can mean anything from mixing two qualitative methodologies using triangulation, to integration of quantitative and qualitative methodologies at each stage of the study (Anguera et al., 2018). As such, in the absence of agreed guidelines, a consistent critique of mixed method studies is difficult (Anguera et al., 2018, Doyle et al., 2016, Mertens and Hesse-Biber, 2013).

Deciding whether a study is mixed or multi methods is equally complex. The key difference proposed between mixed and multi-methods study is integration (Andrew et al., 2009, Anguera et al., 2018, Doyle et al., 2016, Shorten and Smith, 2017). Mixed methods involve integration at one, or multiple, stages of design, methods, reporting, or interpretation (Bryman, 2007, Creswell, 2014, Mertens and Hesse-Biber, 2013, Shorten and Smith, 2017, Yardley and Bishop, 2015). Therefore, integration, at an appropriate stage, is a key element of a mixed method approach (Andrew et al., 2009, Anguera et al., 2018, Bryman, 2007, Doyle et al., 2016, Shorten and Smith, 2017, Yardley and Bishop, 2015), with some advocating research should not be defined as mixed methods if integration is absent (Bryman, 2007).

As the field grows, the need to highlight the difference between mixed and multi-methods studies has become more important (Anguera et al., 2018). *“Multi-method research is when different approaches or methods are used in parallel or in sequence but are not integrated until inferences are being made”* This approach can involve combining multiple qualitative methodologies, as well as mixing quantitative and qualitative approaches. It is not only multi-methods, but multi-analysis, with each separate research question answered with appropriate methodology, before collating results at the end. With this approach different work packages within one study can be viewed as standalone studies. Multi-method approaches are gaining prominence particularly for those sceptical regarding the appropriateness of integration, with legitimate questions regarding for example “quantising qualitative” data, or the converse (Sandelowski, 2014, Sandelowski et al., 2009).

This thesis takes a multi-method approach: the different types of knowledge generated by this work were thought to be complementary but separate; it would not be appropriate to integrate the findings. The best way to understand the findings and ultimately answer the study aim of gaining a deeper and fuller understanding of Capacity in the context of multimorbidity and SED, was to treat the work packages as standalone studies, before reflecting on how the findings related to one another. This provided deeper, richer answers to the original questions because the different types of knowledge generated informed one another.

4.4 The role of theory

As discussed in Chapter 3, the research questions, and methodologies for this work were shaped by BOTT and particularly the key construct of capacity. An abductive approach was taken where this work did not seek to “test” BOTT in the way a traditional positive deductive stance might. Rather it aimed to understand if the constructs contained within BOTT are applicable in the context of multimorbidity and socioeconomic deprivation. It informed the design of each of the work packages but, particularly in the qualitative review and work package, an iterative approach ensured wider themes not currently related to BOTT could emerge.

4.5 Reflexivity

The subtle realist stance taken in this work acknowledges the researcher is not independent of the knowledge generated. Therefore, I as the main researcher regularly reflected on how my knowledge, beliefs and experience influenced my interpretations, and how my presence itself may have influenced the data generated. Such reflexivity is central to qualitative enquiry and encourages reflection on the impact of the research process.

One of the key things I was aware of is my differing life experience in comparison to many of the participants. I am a white, middle-class GP, representing a large local university. All of these introduced a power dynamic into the data generation process. Reflecting on this throughout the fieldwork process, analysis and interpretation was essential. In addition, as a practicing GP I have years of experience working in communities like the research field. Thus, interpretations would undoubtedly be coloured by my experience. This required careful reflection to ensure interpretations were from the data, while recognising I can never fully separate myself and my experience from the interpretive process. I also brought an underlying medical knowledge to this study and had to make clear distinctions between being a GP (especially as some participants were aware of this), and the researcher role. This required intentionality to listen, observe and seek to understand, rather than my clinical role which is to find solutions.

Furthermore, there are “softer” identities that influence how I experience life: I am in my early 40s, am female and a mum; I also am a Christian and this worldview influences how I understand reality. Being aware of these identities, how they influence my interpretations and constantly questioning them was important, as is making them explicit so that the results can be interpreted within that context.

Chapter 8 discusses the quantitative work packages and describes in detail the steps I took to ensure the assumptions underlying the data analysis was grounded in wider perspectives than just my own. For the qualitative work I practiced regular reflection, writing field notes after interviews and making space for reflection in each of my participant observation notes. I regularly discussed my emerging findings, my thoughts and how it was all impacting me with two of my supervisors. These discussions were invaluable as interpretations emerged to explain and ensure they were grounded in the data.

Even with these checks in place I did have one difficult experience early in the data collection process when one of the interviewees disclosed previous abuse and current suicidality. My innate GP training did kick in, safety netting and managing risk is something I subconsciously do. However, the whole experience was very disorientating for me, I felt completely torn and uncertain about my responsibilities. During the interview I explained I would need to inform their GP of the suicidality, which the participant agreed to. I was able to have a long conversation with one of my supervisors immediately after to ensure that I had done everything I should have done. This allowed me to explore just how embedded my identity as a GP was, far more than I had ever realised. Disclosures of abuse are not uncommon for me in daily practice, but how to manage it in this context threw me.

This incident happened during the second lockdown, reflecting on it made me realise just how much I had underplayed the stress I was feeling about trying to juggle clinical, academic, and family roles and that I was much more stressed than I had previously appreciated. It made me aware my professional identity was deeper than I had previously realised. I slowed down my rate of interviews, and rather than the “just getting tasks done” stance I had fallen into (a common reaction I suspect of many doctors when pressure increases) I intentionally took time before each interview, and each participant observation session, to remind myself my role was to inquire and understand. I also recognised the need to take time to notice my emotions and any underlying stresses, and to protect time to make sure I was looking after myself, and my family. Finally, it also revealed the juxtaposition of being a novice researcher, but an experienced GP. I had to work to stop interviews, and discussions with participants, becoming therapeutic encounters.

The purpose of this section is to be explicit about the underlying assumptions, beliefs, and experiences I have that frame how I approached and analysed the data. The results of this work are to be interpreted recognising, particularly in the qualitative findings, they are a construction of both the participant’s experience and my perception of it.

4.6 Conclusion

This chapter summarises the traditional epistemological and ontological stances researchers take, and justifies the subtle realist stance, and multi-method approach chosen for this work. It highlights the importance of reflexivity, expanding on key characteristics of the researcher which may have influenced interpretation. Chapter five builds on this to describe the methodological design of this work.

Chapter 5 Methodological Design

5.1 Introduction

5.1.1 Aim

This chapter discusses the specific methodological design each work package utilised to answer the research questions. It also describes the impact of the Covid 19 pandemic on this work.

5.1.2 Rationale

Chapter four discussed the epistemological stance of this thesis and argued the value of multimethod research. This chapter outlines the methodological design and tools used and the research questions in each of the three work packages:

Work Package 1: Qualitative systematic review

1. For current primary, or community, care multimorbidity interventions:

    a) Do they address self-management, treatment burden, patient capacity or socio-economic deprivation?

    b) What is the experience of participants, and what are the components of the interventions that they value or perceive to be of particular benefit?

Work Package 2: Quantitative analysis

2. What is the impact, if any, of individual or community factors on mortality and healthcare utilisation?

Work Package 3: In-depth qualitative analysis

3. What are the key factors that impact capacity to self-manage in people with multimorbidity living in areas of high socio-economic deprivation?

4. How do community beliefs and resources enhance, or limit, capacity at an individual level to manage long-term conditions?

5.2 Qualitative Systematic Review

5.2.1 Can you synthesise qualitative literature?

Consideration should be given as to whether the nature of qualitative literature precludes it from formal and systematic synthesis. The importance and role of systematic reviews in quantitative literature, often considered the most robust evidence (Cochrane Library, 2021), is well-established (PRISMA, 2020). Quantitative evidence, by its nature reproducible, lends itself well to systematic reviews with established statistical methodology regarding meta-analyses and reporting (PRISMA, 2020). Although, even in this context aggregating results can be problematic because of study heterogeneity.

Qualitative studies involve small samples “grounded” in the local context of the study (Green and Thorogood, 2018); it is less clear whether these results can, or even should, be aggregated (Barnett-Page and Thomas, 2009, Nicky Britten, 2011, Heaton, 2004, Mason, 2007, Mauthner et al., 1998, Niamh Moore, 2007, Parry and Mauthner, 2005, Parry and Mauthner, 2004, Popay et al., 1998). Some believe qualitative data cannot be reused on epistemological grounds, as it is reflexively produced between researcher and participant, so can only fully be understood by the original researcher (Mauthner et al., 1998, Parry and Mauthner, 2005, Parry and Mauthner, 2004). Many others, however, believe synthesising qualitative studies is valuable and can provide crucial insights (Nicky Britten, 2011, Heaton, 2004, Popay et al., 1998).

An important reason to consider synthesising qualitative data is that that not all research questions are best, or indeed can be, answered by quantitative data alone (NICE guidelines, 2012). Two of the papers identified for the review conducted for this PhD exemplified this: mixed methods evaluations of interventions (Edlind et al., 2018, Sussman et al., 2016). The quantitative findings were inconclusive, or minimal, while the qualitative analysis provided important additional insights. Complex health care systems require evidence beyond treatment efficacy to consider how, why and for whom interventions work (Hawe et al., 2004, Skivington et al., 2021). Qualitative research goes beyond understanding efficacy by exploring participant experience, allowing a deeper understanding (Green and Thorogood, 2018).

In addition, primary research is expensive, and time consuming; qualitative synthesis ensures an efficient use of data already available (Heaton, 2004, Ziebland and Hunt, 2014). While never a reason not to carry out primary research where necessary, there is an ethical imperative to ensure maximum use and benefit is gained from the time and effort participants take to share their stories and experiences (Innes, 2006).

Further, qualitative synthesis is part of the “investigative epistemology” (Mason, 2007, Niamh Moore, 2007) of qualitative research which is about *“energetically and creatively seeking out a range of data sources to answer pressing research questions in quite distinctive ways, as well as about using those sources critically and reflexively”*(Mason, 2007). Well-established qualitative synthesis methodologies which can produce high quality rigorous results can inform policy and clinical practice (Nicky Britten and Pope, 2011, Dixon-Woods et al., 2006, France et al., 2019, Heaton, 2004, Noblit, 1988).

In their simplest forms qualitative reviews take an aggregate approach of combining findings, looking for similarities, to answer the research question with greater certainty than a single study (Barnett-Page and Thomas, 2009). However, qualitative research has a rich methodological background of interpretation (Green and Thorogood, 2018), and such analytical principles are applied in several synthesis methodologies. This creates interpretative reviews grounded in the data that can reveal new insights and generate theory (Barnett-Page and Thomas, 2009, Nicky Britten and Pope, 2011, Dixon-Woods et al., 2006, Noblit, 1988).

In summary, this section argues that while synthesis of qualitative data introduces challenges, the use of high quality and rigorous established methodologies can produce important insights and knowledge not gained from individual studies alone. Indeed, qualitative literature syntheses can, and should, be done but must acknowledge the issues in combining different studies and interpreting findings in that context (Barnett-Page and Thomas, 2009, Nicky Britten and Pope, 2011).

5.2.2 Developing the research question

A key process in conducting any systematic review is developing an appropriate research question: too broad (particularly in an area such a multimorbidity) and the volume of literature identified becomes unmanageable; too narrow risks the insufficient number of studies.

The initial research question was:

- Do current interventions aimed at multimorbidity address self-management, treatment burden, patient capacity or socio-economic deprivation, and if so, how?

Initially a wide search identifying all potential papers describing multimorbidity interventions (both qualitative and quantitative papers) was planned to explore the extent to which treatment burden, capacity, social context, and self-management were examined. During scoping searches, and in discussion with an information scientist, it became clear that ensuring a wide enough search strategy that produced a manageable search yield would be challenging.

A search strategy developed for a Cochrane review examining the efficacy of current multimorbidity interventions (Susan M. Smith et al., 2021) was considered and judged to be a reasonable starting point to develop a relevant search strategy. The intention was to update the search, which was originally conducted in 2016. However, through correspondence with the review authors it emerged the review had been recently updated though, in keeping with their previous searches, qualitative research was excluded. A parallel scoping search revealed increasing numbers of interventions for people with multimorbidity, but few qualitative explorations of the participant experience. There was scope therefore to conduct a purely qualitative review. Moreover, a qualitative approach was thought appropriate to fully explore the high order constructs of BOTT.

In response to the scoping search, the research questions were refined. The final formulation of research questions for the review were:

1. For current primary, or community, care multimorbidity interventions:
    a. What is the experience of participants, and what are the components of the interventions that they value or perceive to be of particular benefit?
    b. Do they address self-management, treatment burden, patient capacity or socio-economic deprivation (SED)?

5.2.3 Locating Relevant Papers

Search strategies for qualitative reviews vary enormously depending on underlying approach, and context. Some employ a rigorous systematic search, ensuring all relevant evidence is identified and considered (PRISMA, 2020). Other qualitative literature methodologies take a deliberately iterative approach to purposively identify relevant papers (Barnett-Page and Thomas, 2009, Dixon-Woods et al., 2006).

Given that this review was carried out in the context of health services research, where a systematic search is a hallmark of quality, and that the preliminary scoping searches, and wider knowledge of the multimorbidity literature, confirmed a paucity of articles regarding participant experience of multimorbidity interventions, the decision was made to undertake a systematic search to maximise the identification of relevant studies.

Conducting a systematic review in the context of multimorbidity is complicated. The term ‘multimorbidity’ has been widely used only recently and was not classified as a MeSH search term until January of 2018 (US National Library of Medicine, 2021). Therefore, the search terms had to be broad to pick up relevant studies. The final search strategy was adapted from the Cochrane review of efficacy of multimorbidity interventions (Susan M. Smith et al., 2021) which, although complex, would identify potential interventions targeting two or more chronic diseases. A qualitative filter replaced the original search terms identifying quantitative study designs.

Systematic search for qualitative studies can be challenging because studies are often not explicitly classified as qualitative within databases (DeJean et al., 2016, Shaw et al., 2004). Both qualitative researchers and information scientists have considered how best to undertake qualitative searches and developed multiple qualitative search filters, of differing complexity (Canadian Health Libraries Association, 2021, DeJean et al., 2016, ISSG Search Filter Resource, 2021, Shaw et al., 2004, University of Texas School of Public Health, 2021). Reviews of different filters demonstrated no one type consistently identifies all potential articles (Shaw et al., 2004), and filters with high sensitivity achieve this at the expense of high false positives (DeJean et al., 2016). The choice of filter therefore is carefully balanced to guarantee that all relevant studies are identified, while not identifying so many potential studies that the yield becomes untenable (DeJean et al., 2016).

Five potential qualitative filters (Canadian Health Libraries Association, 2021, DeJean et al., 2016, ISSG Search Filter Resource, 2021, Shaw et al., 2004, University of Texas School of Public Health, 2021) were identified. Citation and reference searching of the list of final articles of the most recent Cochrane review update (kindly emailed by the authors) identified four key relevant qualitative papers. Five searches, each using a different filter were conducted on one database, Medline. All key papers were identified irrespective of filter, though different filters produced variable yields. These results were reviewed with project supervisors; it was felt the more detailed filters were more specific to sociology, searching specific theoretical constructs and methods not relevant in this context. In contrast, while the simplest filter identified key papers, the paucity of literature in this area indicated that a broader search would be more appropriate. The filter chosen (University of Texas School of Public Health, 2021) identified all the potential papers and 6671 articles. The full adapted search strategy is in Appendix 2. The search was designed to also identify mixed methods articles. Where these included significant presentation and discussion of qualitative results to allow a synthesis then these were included.

5.2.4 Quality Appraisal

While the process of appraising quantitative evidence is well-established, applying appraisal tools to qualitative evidence is more nuanced. Some argue the processes and aims of qualitative work challenge the use of fixed criteria (Popay et al., 1998). However, not appraising qualitative work risks over-reliance on potentially poor-quality work; inferences can still be made but reporting must be transparent.

Some argue as quantitative and qualitative methodologies share broad qualities (reliability, validity, generalisability and objectivity) appraisal should be approached in a similar manner (Popay et al., 1998). However, as the markers of quality are different, simply applying quantitative criteria could miss signs of high quality (Popay et al., 1998).

This review used the Consolidated Criteria for Reporting Qualitative Research CORE Q tool (Tong et al., 2007), to appraise the qualitative data. It is a well-established, qualitative checklist widely used in health care research and allows appraisal across a range of study methodologies, including multiple methods. The checklist asks questions across three domains:

- Research team reflexivity
- Study design
- Analysis and results

CORE Q does not aim for positive answers: a negative answer does not necessarily indicate poor quality. Furthermore, checklists can oversimplify signs of rigour; just because a theoretical framework is mentioned does not mean the methodology followed established principles. Therefore, the appraiser is required to do more than identify potential markers of quality, they also must explore and question statements authors make when reporting findings (Nicky Britten, 2011).

Finally, when applying appraisal criteria, the question of excluding studies deemed poor quality is potentially problematic (Nicky Britten, 2011, Majid and Vanstone, 2018, Popay et al., 1998). Doing so would prioritise certain studies (e.g. complex theoretical findings at the expense of descriptive studies) (Majid and Vanstone, 2018), potentially excluding valuable information. In addition, quality may depend more on researcher experience and ability than methodological approach (Majid and Vanstone, 2018). Checklists may miss relevant factors like originality of research or analytical rigour (Majid and Vanstone, 2018). Most therefore advise not excluding based on quality appraisal (Barnett-Page and Thomas, 2009, Nicky Britten, 2011, Majid and Vanstone, 2018, Noblit, 1988), and that approach was taken in this thesis.

5.2.5 Data synthesis

There has been an explosion of literature reviews – of all methodological types- in recent decades (Sutton et al., 2019). The research field is crowded, with new evolving review methodologies, which can have unclear underlying evidence bases or criteria (Sutton et al., 2019). Even where there is rigorous methodology underlying approaches it is not always followed (France et al., 2019, Sutton et al., 2019), or widely understood, by the wider research community (Sutton et al., 2019).

Calls to tighten definitions of review types by providing recognised established criteria and standards have been made in an effort to improve quality (Sutton et al., 2019). This is particularly important for qualitative reviews where the risk of poorly conducted reviews may mean important results are discounted (France et al., 2019). Despite this, there is no agreed categorisation of review type (Sutton et al., 2019) with a wide array of qualitative reviews listing slightly different methodologies (Barnett-Page and Thomas, 2009, Nicky Britten, 2011, Sutton et al., 2019). Table 5.1 summarises the more widely recognised and reported qualitative review methodologies. It includes critical interpretive synthesis (Dixon-Woods et al., 2006, Sutton et al., 2019) as a qualitative methodology (though it includes quantitative and qualitative articles) because it has strong qualitative theoretical underpinning and is interpretative in nature.

Table 5-1 Summary of some of the key qualitative data synthesis methodologies

Method	Description
Meta-ethnography	Rigorous interpretative methodology discussed in detail on pages 70-71.
Grounded Formal Theory	Synthesises existing grounded theory studies to generate higher order theory (Barnett-Page and Thomas, 2009). Grounded theory constructs (concomitant data collection with inductive analysis, theoretical sampling with saturation, constant comparative method, theory generation “grounded” in the data) are applied to qualitative synthesis (Barnett-Page and Thomas, 2009).
Thematic Synthesis	Applies well established qualitative interpretative analytical techniques to the synthesis process. Initial descriptive coding of identified papers before further interpretation using “analytic” codes (Barnett-Page and Thomas, 2009). Mirrors thematic synthesis of primary qualitative data.
Textual Narrative Synthesis	Used for both quantitative and qualitative synthesis, grouping similar studies together. Standard forms record key characteristics, allowing exploration of similarities and differences. Particularly valuable exploring differences between studies (Barnett-Page and Thomas, 2009).
Meta Study	Three stages analysis throughout the synthesis process: findings (meta data), analysis (meta-analysis) and theory (meta-theory) (Barnett-Page and Thomas, 2009). Views qualitative literature synthesis as a secondary analysis, i.e. “a construction of a construction” (Barnett-Page and Thomas, 2009). Interpretivist epistemology allows these underlying contexts of individual studies to be explored. Seeks to generate new insights and interpretations.
Meta Narrative	Developed to inform policy design, synthesis of findings from wide range disciplines. Recognises knowledge produced in the context of different research paradigms underpinned by different theoretical assumptions. Allows synthesis of different research paradigms by identifying key papers for each paradigm and exploring their development over time, creating meta-narratives from which key themes can be extracted and be used in synthesising the studies.
Critical Interpretative Synthesis	Synthesis works across multiple methodologies (quantitative and qualitative) and disciplines (Barnett-Page and Thomas, 2009, Dixon-Woods et al., 2006). Includes an iterative approach to paper selection; contribution to theory development important in determining article quality (Barnett-Page and Thomas, 2009, Dixon-Woods et al., 2006). Critical approach to theoretical underpinning and choice of methodology of included studies. Uses line of argument synthesis to develop “synthetic” constructs, and explicit aim is to develop new theory (Dixon-Woods et al., 2006)
Framework Synthesis	Uses a clear structure to organise and analyse data. Unlike other methods uses pre-existing theory, or concepts, to create an “a priori framework” (Barnett-Page and Thomas, 2009) in analytical approach. New codes may emerge and added to the framework during analysis.

The initial scope of this review was to understand the extent to which social context and BOTT constructs were considered within current primary care multimorbidity interventions. However, during the scoping review the paucity of literature suggested a gap in knowledge regarding the participant experience. It was felt an inductive interpretive approach may yield rich data that could be missed if only taking a deductive approach using BOTT. Therefore, a dual approach was taken, with two analyses conducted.

Firstly, to understand participant experience of current multimorbidity interventions meta-ethnography was chosen which allowed exploration of emerging overarching concepts that may generate new insights and inform future intervention design. To examine how Treatment Burden and Capacity constructs were considered in multimorbidity interventions a framework analysis using BOTT was conducted with a narrative summary of how each paper explored social context. Finally any papers containing self-management components would be classified using the PRISMS self-management taxonomy (Pearce et al., 2016).

5.2.5.1 Meta-Ethnography

Meta-ethnography is a synthesis method originally developed by educational ethnographers (Noblitt and Hare)(Noblit, 1988) as a way to synthesise ethnographic work. Designed *"to develop an inductive and interpretative form of knowledge synthesis" (Noblit, 1988),* it has since successfully synthesised other types of qualitative literature (Atkins et al., 2008, N Britten et al., 2002, Campbell et al., 2003). Whilst extensively used in a variety of healthcare settings (Nicky Britten and Pope, 2011, France et al., 2019, Malpass et al., 2009), there is recognised variation in quality. To remedy this the eMERGE reporting guidance was developed (France et al., 2019).

Noblit and Hare described seven phases in their methodology; the eMERGE guidance made recommendations for each stage in the healthcare context, as well as 19 reporting criteria (France et al., 2019, Noblit, 1988). These phases often overlap, and as meta-ethnography is iterative, phases are often revisited as findings emerge:

1. **Selecting meta-ethnography as a methodology and getting started:** defining research question and rationale for using this methodology.

2. **Deciding what is relevant:** searching and identifying papers.

3. **Reading included studies:** reading and rereading selected studies and initial data extraction identifying key characteristics of different studies. Also involving creating metaphors (can use a grid, table, or software to categorise metaphors).

4. **How studies are related:** exploring how the studies are related – do they relate reciprocally or are their differences (if this is the case how does context influence this).

5. **Translating studies into one another:** methodological foundation of meta-ethnography, a process whereby metaphors are "translated" between the study contexts. Translation can be reciprocal (in agreement) or refutational (where metaphors appear to state different things). First order constructs (original data from participants e.g., quotes) and second order constructs (authors interpretations of the data collected in their reporting in the paper) during the translation process results in new overarching themes (or third order constructs).

6. **Synthesise translation:** third order constructs can be synthesised in three types of translation: reciprocal (where the results from the reciprocal translation are presented), refutational (where metaphors that disagree are presented with exploration of the original context to shine light on the difference) or a line of argument synthesis (a new interpretation which takes the reciprocal and refutational translation and presents them in a new interpretative framework).

7. **Express the synthesis:** the findings of the synthesis are presented, normally, but not exclusively, in an academic paper.

5.2.5.2 Burden of Treatment Theory Analysis

The constructs of capacity and treatment burden in BOTT are discussed in detail in chapter 3. To explore whether these are considered in existing multimorbidity interventions, a second analysis was conducted applying the underlying constructs of BOTT as a coding framework. Previous reviews used Normalisation Process Theory (NPT, 2021) to explore Treatment Burden (K. Gallacher et al., 2013a, K. Gallacher et al., 2011, Katie Gallacher et al., 2013b). The PROSPERO protocol stated the review would use NPT to explore treatment burden, and BOTT to explore capacity. However, as discussed in chapter 3 the construct of treatment burden was underpinned by NPT in BOTT. After discussion with the project supervisors (experts in BOTT and NPT) using BOTT as a conceptual coding framework was deemed the most appropriate way to examine both capacity and treatment burden in the papers identified. An existing framework (Chikumbu et al., 2022) summarising the key BOTT constructs was applied to the identified articles.

5.3 Quantitative work package

This work package set out to answer the second research question:

- What is the impact, if any, of capacity (individual or community) and treatment burden on mortality and self-reported hospital admissions?

5.3.1 Choice of data

This project required a dataset, ideally a cohort, with data on people’s health, as well as a wide range of individual factors, and information about participants’ experience of their community. Ideally, a cohort dataset was preferred over cross-sectional data so potential causal relationships could be explored and to account for variables changing over time within the analysis. A high-quality cohort often answers multiple questions beyond the remit of the initial research team. However, they are time-consuming and expensive to run and unless part of the original cohort design, it may be difficult to find a cohort that contains all the desired variables. In addition, many cohorts struggle to recruit in areas experiencing higher socio-economic deprivation (SED) resulting in under-representation in cohort populations; an issue for this study focusing on multimorbidity in areas of high SED.

5.3.1.1 The West of Scotland Twenty-07 Cohort

The West of Scotland Twenty-07 (WoS 20-07) cohort followed up three age-specific cohorts (aged 15,35,55 at baseline) for twenty years, collecting data and four further waves of data. A variety of variables influencing capacity domains (e.g., transport, social networks, literacy), as well as health and healthcare usage, were collected. It also explored experience of, and feelings about, local community, providing potential community capacity variables.

For the primary outcome of mortality, every participant was linked to the National Registry of Scotland, therefore up to date mortality data was complete. For healthcare utilisation self-reported number of nights in hospital in the last year was available across all five waves. The data were collected in sequential waves which allowed the analysis to adjust for changes over time. As most capacity variables would be expected to vary significantly over time this was an important advantage. Information on multimorbidity was already collected in the data set allowing analysis to be conducted on a sub-cohort experiencing multimorbidity.

A further advantage was the sampling strategy which deliberately recruited a cohort representative of the population (Benzeval et al., 2009), resulting in a population similar, if not slightly more deprived, than the national population according to the 1981 census (Der, 1998). However, when the cohort was recruited (late 1980s) there was considerably less ethnic diversity in the population of the West of Scotland, meaning the cohort is almost exclusively white (98.2%).

Further limitations were firstly, loss to follow up bias. Comparison of characteristics showed those missing were more likely to be from lower deprivation categories and less likely to have multimorbidity. In addition, the questions asked varied between each wave, and even between some of the cohorts within each wave. This missing data had to be adjusted for in the analysis (issues with missingness discussed in more detail in chapter 8).

Whilst acknowledging these limitations, the WoS 20-07 cohort provided a wealth of potential variables, measured over time, in a relatively deprived population that allowed model development exploring the relationship between capacity (individual and community) and treatment burden and the outcomes of interest.

5.3.2 *Mapping potential variables to Burden of Treatment Theory*

The quantitative analysis was initially to be informed by the qualitative work, guiding selection of potential capacity variables. However, due to the covid pandemic (discussed below) study sequence changed and this quantitative work package began before qualitative data collection. Unable to ground variable selection in the qualitative data, the existing literature base and discussion with researchers with expertise in BOTT constructs were used to identify potential capacity variables.

Due to the variation in the data collected across waves, and between cohorts, an initial list of potential variables, and confounders, was compiled by looking through the questionnaires for each wave, and cohort (MRC Social and Public Health Sciences Unit). There were several variables (e.g., self-esteem) that were likely important capacity factors but not asked in each wave. In these situations, either a similar question was used as a proxy, or if that was not an option, and the variable was important, it was discussed with the project supervisors (two experts in BOTT, one statistical expert) before a final decision was made on inclusion. Variables on the list were then mapped to underlying constructs of BOTT (table 5.2), adapted from an existing taxonomy (Chikumbu et al., 2022).

Table 5-2 summarising initial mapping of potential variables to BOTT constructs

Capacity – Individual		**Potential variables from WoS20-07**
1: Mobilising capacity – Capacity of individuals and their relational networks to interact and utilize healthcare services		
1.1: Agency	Things people do to engage with health problems and with others: impact of physical/psychological/sensory aspects of disease and disability; material and cognitive resources at their disposal	Equivalised income; struggle to pay bills; struggle to pay for luxuries; housing tenancy; satisfaction with housing; car access; employment; job quality; life events (sig job changes, sig diagnoses/change in health
1.2: Relationality	Social networks through which agency can be expressed and distributed:	Number family contacts/month; number non-family

	intensity, size, and complexity of relational networks (which may vary over time). Will include health professionals	contacts/month; someone to confide in; number of children in house; someone for practical support; loneliness ; life events; caring responsibilities
S 1.3: Opportunity	Availability of services varies by time and area.	No relevant variables
1.4: Control over service	What organisations do to determine the content, structure, and resources of services.	No relevant variables
2: Expressing capacity – the qualities patients and their relational networks need to possess if they are to exploit healthcare opportunities.		
2.1: Social Skill	Skills necessary to engage and mobilise the cooperation of others, and to negotiate controls placed on resources to help with the tasks of care.	Self-esteem: personality (need to choose the factors interested in); self-reported health; health compared to others your age; health locus of control; life events(deaths/marriages/family)
2.2: Functional Performance	Degree to which people possess the cognitive and material capacity to meet demands.	Disability; limiting long-term illness; HADS; education; AH4 (literacy/numeracy measure);
2.3: Structural resilience	How the patient's network of support can be used to absorb, compensate, and even thrive when things change.	No relevant variables
2.4: Social Capital	How the patient's social network can be used for gaining information and resources that help with care.	Number of community groups involved in; exchange small favours with neighbours;
Treatment Burden (BOTT Categories)		
3: Mobilising and enacting delegated tasks – how patients sustain and modify their role (including self-management)		
3.1: Sense Making (coherence)	The way sick people and their social networks identify, understand, and explain the diverse tasks that make up work, internalize these and plan for their requirements	No relevant variables
3.2: Building and maintaining relational networks (cognitive participation)	How patients and their networks enrol, engage, and maintain contacts in their support network.	No relevant variables
3.3: Enacting delegated work (collective action)	How patients and their networks allocate and execute specific tasks, negotiate accountability for outcomes and organise and realise the mobilisation of resources	No relevant variables
3.31: Material and cognitive practices to be done (interactional workability)	Whether tasks are perceived to be workable, and how patients navigate their different responsibilities.	No relevant variables
3.33: Practical Help (skill set workability)	Having or obtaining the practical skills to carry out care tasks.	No relevant variables
3.34: Exploitable resources	Having or obtaining the resources to carry out care tasks.	No relevant variables

(contextual integration)		
3.35: Confidence in outcomes (relational integration)	Factors that influenced whether carers had confidence in the outcomes of delegated tasks.	No relevant variables
3.4: Reflexive monitoring	Collecting information regarding sign and symptoms and vies of sig others, undertake its individual and collective appraisal, and apply it to the reconfiguration of their work	No relevant variables

The cohort was clearly not designed to explore BOTT constructs and as such there was not sufficient data to allow in-depth exploration of the sub-sections of the capacity constructs. In addition, there was a paucity of variables measuring the higher order concepts related to mobilising and enacting delegated tasks. In discussion with the project supervisors, it was agreed to collapse and simplify these constructs. A further group of variables were collected under the heading “community capacity” – measures of how participants viewed and experienced their wider community. This allowed the mapping of all potential variables to four key constructs: Individual Capacity (Mobilising), Individual Capacity (Expressing), Community Capacity and Treatment Burden (table 5.3)

Table 5-3 Table summarising simplified BOTT constructs with their potential variables, outcome variables and potential confounders.

Constructs	Potential Variables
Individual Capacity: Mobilising Capacity of individuals and their relational networks to interact and utilize healthcare services	Income; car access; housing tenancy; employment status; Death family member or friend, divorce, unemployment, or job change in last year; number family contacts/month; number friend contacts/month; someone to share feelings with; someone to confide in; someone to offer practical support; loneliness; carer
Individual Capacity: Expressing The qualities patients and their relational networks need to possess if they are to exploit healthcare opportunities.	Self-esteem; self-reported health; health compared to others your age; health locus of control; mastery; disability; limiting long-term illness; HADS; education; AH4 (literacy/numeracy measure); Number of community groups involved in
Community Capacity Characteristics belonging to the wider community that could have the potential to enhance/diminish capacity	Feelings about community; walking in the dark; neighbourliness; problems in community
Treatment Burden The Work patients do to manage their multimorbidity	Medication; number GP visits/house calls; number outpatient visits
Outcomes	Primary: mortality Secondary: self-reported number nights in hospital

Potential confounders	Age; ethnicity; gender; BMI; BP; smoker; alcohol; marital status; deprivation status; fruit and veg consumption; exercise

5.3.3 Direct Acyclic Graphs

Causal inference, and inferring what is caused by an explanatory variable, rather than a potential confounder, is a complex process. Randomised Controlled Trials (RCTs) are a gold standard way to test causal inference as the randomisation process allows a degree of confidence that the causal estimate is measuring the explanatory variable of interest (Bonita R, 2006). However, it is not feasible, and often unethical, to carry out RCTs in many situations meaning researchers require to use observational data to explore causal associations. This becomes very complex, with researchers required to understand, and potentially adjust for multiple biases (confounding, selection, information) (Tennant et al., 2019). Adjustment for potential confounding variables is used to mediate this, but often the process behind the choices of confounders are not explicitly discussed (Tennant et al., 2019). In recent years this has led to recommendations to define a *"causal estimand"* prior to any analysis (Rubin, 2005, Tennant et al., 2019). Misidentification of variables can lead to not adjusting appropriately (attributing causal effect to the explanatory variable, rather than the confounder) or over adjusting (potentially missing causal impact of the explanatory variable).

Direct Acyclic Graphs (DAGs) *"are non-parametric diagrammatic representations of the assumed data-generating process for a set of variables (and measurements thereof) in a specified context"* (Tennant et al., 2019). They are increasingly used in health sciences research to deepen understanding of potential causal pathways and allow the creation of appropriate adjustment strategies (Ferguson et al., 2019, Tennant et al., 2019). How and why they are used varies significantly and there have been calls for guidelines regarding their use and reporting (Tennant et al., 2019). As their popularity has grown, software has been developed to create DAGs and help identify potential adjustments for a proposed model (Dagitty, 2019).

DAGs evidence a transparent demonstration of researchers' understanding of the causal relationship between potential explanatory and outcome variables. They are flexible and when managing complex factors there is an element of subjectivity in decisions regarding potential causal pathways (Ferguson et al., 2019). They can inform analysis adjustment strategy, often based on existing evidence to increase rigour (Ferguson et al., 2019), with the accuracy of any adjustment strategy dependent on how closely the causal diagram coincides with real life (Tennant et al., 2019). The construction of a DAG provides an explicit and transparent explanation of the assumptions that underly an analysis (Ferguson et al., 2019, Tennant et al., 2019) allowing interpretation and challenge of results more easily.

It was important that the potential causal pathways the analysis was based on were explicit and rooted in current literature. In addition, as the WoS 20-07 cohort was not designed to specifically measure BOTT variables, exploring important unmeasured variables was of value.

A DAG was constructed for each construct to explicitly conceptualise how potential variables and confounders influenced outcomes. The sheer number and complexity of factors meant it was not possible to do a literature review for each variable, one of the approaches advocated (Ferguson et al., 2019). Therefore, initial potential pathways, based on understanding of current literature, were discussed with various experts in this area. In addition, a PPI representative from the University of Glasgow Primary Care PPI group was recruited to comment on and discuss the DAGs as they were created. This led to consensus on variables and confounders, and the relationship between them.

5.3.4 Measuring outcomes

Due to data linkage with the National Records of Scotland, up to date mortality data was complete as of March 2020, which meant no missing data for the primary outcome. Self-report of the number of nights spent in hospital (in total) in the last year was the only hospital utilisation question asked across all five waves, and cohort, so this was used as the secondary outcome measure.

5.3.5 Statistical techniques

Standard statistical techniques were used to conduct data analysis and are discussed in chapter 8. The relationship between the different groups of variables and mortality was explored using cox regression analysis with time varying covariates. The relationship to hospital admission was explored using multiple regression. As discussed above, adjustment for potential confounders was informed using DAGs.

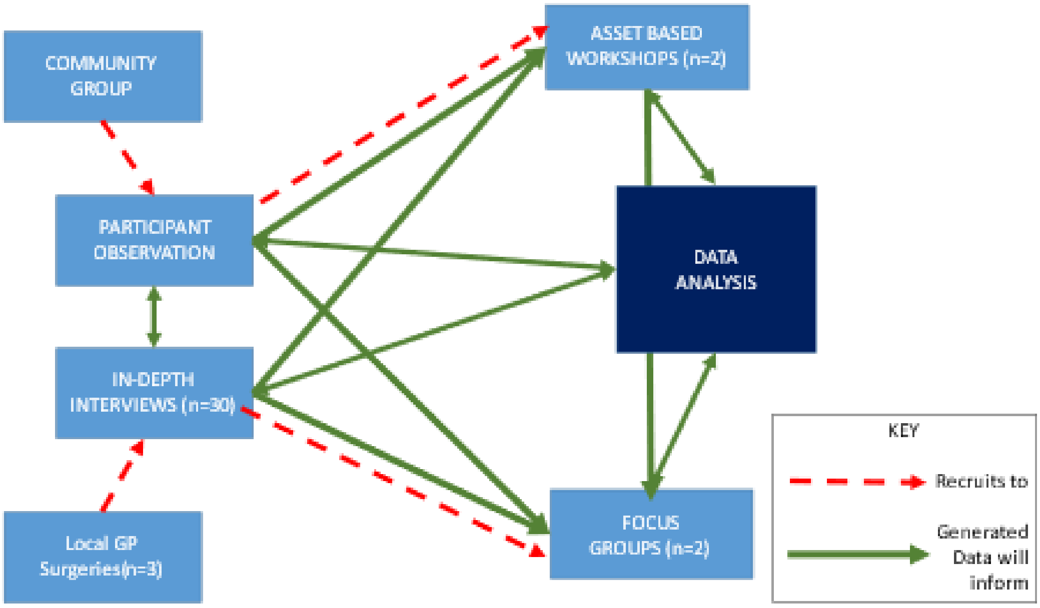
5.4 Qualitative work package

This work package specifically set out to answer the two remaining research questions:

- What are the key factors that impact capacity to self-manage in patients with multimorbidity living in areas of high socio-economic deprivation?
- How do community beliefs and resources enhance, or limit, capacity at an individual level to manage long-term conditions?

Qualitative methodology is best placed to explore socially situated experiences and perceptions. Subtle realism recognises the value of triangulation of qualitative methods to enhance data collection (Eileen Murphy et al., 1998). An ethnographically informed approach was taken that drew on participant observation in four community groups as well as in-depth interviews, which were separately recruited. Validity of emerging results were explored using focus groups with the interviewees, and asset-based workshops with people involved community groups. These workshops incorporated participatory health research (PHR) principles to allow participant contribution to the analytical process. How these different methodologies were recruited and relate to each other is summarised in figure 5.1. The covid pandemic impacted this work package the most, this and the mitigations made are discussed in the final section.

Figure 5-1 Figure summarising the different qualitative methodologies and how they related to one another



5.4.1 *Ethnographically Informed Approach*

Originally developed within the discipline of social anthropology, ethnography allows in-depth understanding of previously unknown cultures (Atkinson et al., 2001, Malinowski, 1922). It was further developed by social scientists at the University of Chicago where several landmark ethnographies were produced (Atkinson et al., 2001, Deegan, 2001). Here ethnographic work transitioned to include exploration of urban subcultures, the world of work and complex organisations (Deegan, 2001). Ethnography is marked by intensive time and emersion in the field, participant observation and using writing (both fieldnotes and final report) as an analytical tool (Robert M. Emerson et al., 2001, Green and Thorogood, 2018).

Ethnographers seek to understand the social world by capturing an insider's perspective (Robert M. Emerson et al., 2001, Hammersley, 1992, Rock, 2001). However, any "insight" is the researcher's construction rather than a true insider's account (Rock, 2001). The ethnographer seeks to be a participant, and understand the world from the community's perspective, while maintaining their observer status (Robert M. Emerson et al., 2001, Rock, 2001). This permits questioning of phenomena no longer noticed, or deemed unimportant, by the community (Rock, 2001). Balancing this tension of participant and observer is key to ensure an authentic understanding of the culture and allow description and analysis of findings (Robert M. Emerson et al., 2001, Rock, 2001).

Ethnography is iterative, seeking to understand and describe the multiple layers and interactions observed (Robert M. Emerson et al., 2001, Rock, 2001). This results in what Geertz described as *"thick description"* (Geertz, 2017). It also requires a constant posture of reflexivity, with an awareness of the impact of personal beliefs, assumptions, and experiences (Robert M. Emerson et al., 2001, Green and Thorogood, 2018, Hammersley, 1992, Rock, 2001).

5.4.1.1 Public and Private Accounts

The social world is complex, constantly evolving, with unwritten rules and rituals an outsider will only see over time (Hammersley, 1992, Rock, 2001). Cornwall's (1984) ethnography on health in families in London's East End first described "public" and "private" stories. Participants initial stories articulated positive narratives regarding their communities or healthcare – their "public story". Over time, as trust was built, experiences shared were more likely to include deviant behaviour, negative experiences and criticism of healthcare (Cornwell, 1984). In addition, observation demonstrated behaviours and actions that deviated from their "public stories"; these "private stories" and observed experiences revealed important knowledge of how people acted, and why, in real life context.

5.4.1.2 Influence of Shame

Wider societal experiences shape how health is understood, and how agency is enacted (Bourdieu et al., 2010). Often, despite recognising the importance of social determinants, individuals internalise blame for unhealthy behaviours (Bourdieu et al., 2010, K. Garthwaite and Bambra, 2017, Katherine E. Smith and Anderson, 2018). Health inequality research demonstrates that individual shame and blame directly impacts people's willingness to discuss and explore health and health behaviours (Hatzenbuehler et al., 2013, Peacock et al., 2014, Katherine E. Smith and Anderson, 2018). Given the likely influence of deeply ingrained internalised societal beliefs taking an ethnographically informed approach building trust aimed to reduce stigma and create safe spaces to allow discussion of difficult experiences.

5.4.1.3 Field Notes

While anthropology advocates splitting descriptive fieldnotes from a personal diary (Robert M. Emerson et al., 2001, Malinowski, 1922), this project took the approach of social science where ethnographies produce field notes combining descriptive narrative with reflections of events and the impact on the researcher (Robert M. Emerson et al., 2001). Either process of reflexivity allows exploration of how the work is influencing the researcher's beliefs and emotions. The field notes provide a crucial record of the knowledge derived (construction by the researcher based on their interactions with the field) (Robert M. Emerson et al., 2001).

Ideally field notes should be as "close" to the field as possible (Robert M. Emerson et al., 2001, Green and Thorogood, 2018), although notes written hours to days after the field work can still produce rich "thick description" (Geertz, 2017). In this project, notes were written as soon as possible after observation, and a notebook to jot down contemporaneous notes was also used. To aid reflection notes were written on the same template each time (Appendix 8).

To ensure as full and expansive account as possible, notes were written freely aiming to get as much information and memory down as quickly as possible (Robert M. Emerson et al., 2001). These notes contain rich, highly identifiable data that could not be published. Once field work was carried out, a final analytical writing phase (Robert M. Emerson et al., 2001, Rock, 2001) occurred. Narrative summaries are used to display findings in the results section due the complex and identifiable nature of the field notes themselves. Appendix 13contains a selection of field notes to demonstrate examples of how they related to a selection of themes.

An ethnographically informed approach was chosen as it allowed rich, in-depth understanding of both individual and community capacity. It allowed exploration of both public and private stories, observation of real time actions, and building of relationships over time. This permitted a deeper understanding of how shared community capacity and experience influences individuals, particularly in the context of multimorbidity.

5.4.1.4 Ethnographically informed approaches in health care research.

This approach is well-established within health care research settings (Bloor, 2001). Initial approaches focused on medical professional interactions, before exploring the lived experience of different diseases, in-patient experience and MDT working (Bloor, 2001, Bunce et al., 2014, Cramer et al., 2018, Grant et al., 2017, Grant and Collier, 2018, Grant and Guthrie, 2018). Health Care Research often requires multidisciplinary working in clinical and academic disciplines; ethnographically informed approaches bring a greater depth and breadth of knowledge to larger projects, or contribute to understanding complexities of implementation within a health environment (Bunce et al., 2014).

5.4.2 In-Depth Interviews

Interviews can vary from naturalistic conversations where data is opportunistically gathered to structured standardised survey questions (interviewer seeks to be neutral) (Green and Thorogood, 2018, Kelly, 2010). In-depth, or semi-structured, interviews sit in the middle of this spectrum where the interviewer guides the interview using pre-existing questions and prompts, but where the responders answers direct what is explored (Green and Thorogood, 2018). It allows the in-depth exploration of personal experiences, with data collected socially constructed between the interviewer and interviewee (Giacomni, 2010, Kelly, 2010). What people claim during these interviews cannot be checked, the value is in providing insight into their perceptions, understanding and experience (Green and Thorogood, 2018, Kelly, 2010).

In-depth interviews were chosen to complement the participant observation, and to explore in detail the individual experience of multimorbidity in the context of high SED. A purposive sample was taken from people with at least three chronic diseases, recruited via GP surgeries. Interviews do not occur in isolation and the setting is important (Green and Thorogood, 2018, Kelly, 2010); in this project due to covid restrictions several interviews required to be undertaken over the phone. Once restrictions lifted, participants were still given the opportunity to speak on the phone, or face to face at home. Traditionally, carried out face to face, telephone, and recently online, in-depth interviews have become increasingly popular (Gothberg et al., 2013, Irvine, 2011, Sturges and Hanrahan, 2004, Sweet, 2002). Telephone interviews are shorter, and may have less participant elaboration (Irvine, 2011), but there is little difference in quality of transcripts produced (Sturges and Hanrahan, 2004). It is recognised as a valid way to collect qualitative data (Sturges and Hanrahan, 2004, Sweet, 2002).

5.4.2.1 Participatory Research Methods

Participatory Health Research (PHR) is a growing area of research with broad and diverse disciplines and methods (International Collaboration for Participatory Health Research, 2013). Experts within the field advise it should be considered a paradigm whose methods embrace a range of epistemological positions; considered a particular benefit (International Collaboration for Participatory Health Research, 2013). PHR seeks to provide *"a means for people most affected by health problems to influence how these problems are addressed in society"* (International Collaboration for Participatory Health Research, 2013). Therefore, active participation of the population the research seeks to impact is at its core. Truly embedded patient participation is lacking at most levels of clinical and academic general practice (Anne E MacFarlane, 2020).

A PHR approach involves active participation embedded from design right through to results dissemination, with critical reflexive examination of power dynamics – in both the community experience and the research process (International Collaboration for Participatory Health Research, 2013). This work, while not designed as a PHR study (research questions determined by academics) followed many PHR principles, including recognising knowledge was co-created between the participants "insiders" and the researcher "outsider". Furthermore, during the analytic phase of the study it engaged directly with participants to allow them to contribute to refining emerging results. It also explored using asset-based community development (ABCD) as a participatory method.

5.4.2.2 Refining Results through Participant Feedback

This work purports while social knowledge can never be definitively known, we can reach conclusions we have reasonable confidence in (Hammersley, 1992). Enhancing that confidence requires recognising the influence of the main researcher's background (professional and personal), and life experiences.

Therefore, feedback with participants firstly allowed “sense checking”. There is debate into the weight given to participant feedback (Robert Emerson and Pollner, 2008, Robert M. Emerson et al., 2001, Rock, 2001), and it can be problematic, particularly when sensitive subjects are discussed (Robert Emerson and Pollner, 2008, Robert M. Emerson et al., 2001, Rock, 2001). Agreement, or lack of, is not necessarily a measure of accuracy; when misunderstandings and disagreement arise, this process allows a deeper exploration of results.

In this work the value of participant feedback was firstly that discussion from this process allowed reflection on the validity of the results produced (Robert Emerson and Pollner, 2008, Rock, 2001). Secondly, this process allowed incorporation of PHR principles including the participant voice within the analysis process, producing findings the participants have actively been involved in producing.

Two different methods were used to feedback results: focus group and asset-based workshops. A focus group was chosen to feedback findings to interviewees because they are ideally suited to exploring group processes, including shared knowledge and experience (Barbour, 2010). The group setting allows people to explore and potentially recognise communal beliefs and assumptions, while discussing differences (Barbour, 2010, Green and Thorogood, 2018).

5.4.2.3 Asset Based Workshop

Asset-based approaches have been widely used in the field of community development and social work, with growing interest for use in health contexts (Foot, 2012, Institute for Research and Innovation in Social Services, 2012, J Mclean et al., 2017). Instead of being deficit focussed, asset-based approaches seek to help communities identify their assets: *“resources that individuals and communities have at their disposal”* (Institute for Research and Innovation in Social Services, 2012). A variety of methods (J Mclean et al., 2017) can be used to identify and mobilise assets (Institute for Research and Innovation in Social Services, 2012). This approach not only maps resources but uncovers unrecognised and overlooked assets (Foot, 2012), while empowering both individuals and communities (Institute for Research and Innovation in Social Services, 2012).

This work originally aimed to use ABCD methods in a novel way to explore the community understanding of assets and capacity at the start of the process. This would have allowed the community to shape the research process by defining and identifying important wider community assets/capacity. This was not possible because of the COVID pandemic. However, it was still felt to be a valuable methodological tool, so it was used to allow participant voice within the analytical process. Situating the workshops at the end of the project built on established relationships; participants were vulnerable and honest, potentially more than they would have been at the beginning and therefore potentially yielding richer results.

5.4.3 Data Analysis

Due to the iterative nature of qualitative work, data collection and data analysis are undertaken in parallel, allowing testing of new ideas as they emerge (Giacomni, 2010, Green and Thorogood, 2018, Rock, 2001). There are numerous analysis options, with the choice dependent on epistemological/ontological assumptions, and underlying study aims. BOTT underpins the development of this project, and the prompts such as topic guides for interviews. However, a purely deductive analytical approach was not taken for several reasons.

BOTT is a relatively new theory; it may not be applicable in this context, and important themes not fitting within its existing constructs were likely to arise. Furthermore, there remains uncertainty about how wider community factors influence the management of multimorbidity in the context of high SED. Therefore, an abductive approach was taken with an initial broad thematic analysis (Braun and Clarke, 2006). Although themes were undoubtedly influenced by an underlying awareness of BOTT, multiple themes that fell outside of the BOTT framework were also present. Interpretation then proceeded by comparing wider themes with the BOTT framework to understand its applicability/utility in answering research questions.

Initially, the data generated from the interviews, and the participant observation were analysed separately but in parallel. However, it became clear that the themes emerging were similar and the data sets were complementary. The analysis was aided by NVIVO and as the process continued the interview and observation data were merged into one full data set. The data from the workshops and the focus group were then added to the data set, with the analysis conducted across the whole thing.

5.5 Impact of Covid 19

The study began in November 2019 and was significantly impacted by the COVID pandemic. Not only did it impact the research but as a practising clinician, and mother of three young school-aged children, it significantly impacted my capacity and resource. I reduced my academic commitment, increasing NHS work as part of the pandemic response. The next section outlines the direct impact the pandemic had on the thesis, and the mitigations put in place to manage this.

5.5.1 Changes in study order

The initial study structure was the literature review first, followed by the qualitative work with the quantitative work nested within this. This allowed the qualitative work to inform the variables chosen for the quantitative analysis.

When the UK wide lockdown started ethical permission was granted for the participant observation and workshops, with an application submitted for the interviews. Some preliminary ethnographic field work had been carried out; the asset-based workshops were being finalised. Lockdown required a change in the planned study order, with the quantitative work brought forward. The planned breadth of the qualitative work also required review.

5.5.2 Methodological impact of Covid

The pandemic impacted the quantitative analysis primarily because the variable choice was to be informed by the ongoing qualitative ethnography and in-depth interviews as discussed in section 5.3.2.

The qualitative data generation was most significantly impacted by the pandemic. Initially the proposed plan had been to begin the data generation with a series of asset-based workshops to elicit understanding of community assets and community capacity. Early findings would be extended by time spent over 24 months with a range of groups within the community. Yet the length of lockdown and social distancing restrictions significantly reduced the time available for fieldwork in Drumchapel. Furthermore, convening a community advisory group to discuss emergent findings was not possible given the time restrictions imposed by the pandemic.

A revised community data generation plan was developed. To maximise the available time the decision was made to focus on four key community groups. It was felt the asset-based methodology would be valuable, so it was kept but moved to the end of the data generation process. The revised plan maximised the relationship building established during the community group work.

Recruitment for individual interviews was similarly affected; ethical approval was a lengthy process because COVID related research was prioritised. The wider strain on NHS resources meant that recruiting GP practices to sample patients was more challenging than originally anticipated. Continued social distancing during the second covid wave meant that the first set of interviews were conducted via telephone.

5.6 Conclusion

This chapter summarises the key methodological consideration for each of the work packages used, and why they were chosen. It also summarises the main ways this work was impacted by the Covid Pandemic. The thesis will now present the findings from each work package over the following chapters.

Chapter 6 Results: Meta-ethnography

6.1 Introduction

6.1.1 Aim

The next two chapters present the results from the systematic review: this chapter describes the search process and the meta-ethnography findings.

6.1.2 Rationale

Interventions targeting improving multimorbidity management in primary care are increasingly being developed due to a sparse evidence base. A Cochrane review concluded what is efficacious in this context remains unclear, in part because of the small number of trials (Susan M. Smith et al., 2021). However, this review excluded qualitative articles, which may provide important insights.

This systematic review aimed to address this gap by answering the following research questions:

- For current primary, or community, care multimorbidity interventions:

1. What is the experience of participants, and what are the components of the interventions that they value or perceive to be of particular benefit?
2. Do they address self-management, treatment burden, patient capacity or socio-economic deprivation (SED)?

Answering these questions required a dual approach to analysis: a meta-ethnography to fully understand the participant experience (RQ1), and a framework analysis using Burden of Treatment Theory (RQ2). This chapter will discuss the search process, identified articles and the findings from the meta-ethnography. Chapter 7 will present the BOTT analysis findings before locating findings from both analyses within the existing literature base.

6.2 Methods

A protocol was developed and registered on PROSPERO, the International Prospective Register of Systematic Review (Appendix 1 - https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=194094)

6.2.1 Searching for Papers

A search strategy was developed that identified qualitative papers describing participant experience of multimorbidity interventions based in primary care that had been evaluated by a randomised trial.

Multimorbidity is a fast-growing, but also new, field of research (Academy of Medical Sciences, 2019). To identify all relevant articles (i.e., those targeting two or more chronic conditions) the search was required to capture all interventions targeting more than one long-term condition (LTC). Not all these studies will include co-morbidity or multimorbidity terms, therefore the strategy required to go beyond simply searching those terms.

Smith et al's (2016) review of multimorbidity interventions developed a thorough search strategy for this purpose. It formed the basis for the search strategy used in this review. The original search excluded qualitative literature, so on the advice of an information scientist, search terms for quantitative study types were removed and replaced with a qualitative filter. Doing so permitted the identification of studies that reported the qualitative components of potential multimorbidity interventions. The most recent Cochrane update (published after initial search was done) has updated the search but this search strategy was based on the one published by the Cochrane group in 2016 (Susan M. Smith et al., 2016).

As discussed in chapter 4, a scoping search tested validity of the chosen qualitative filter before a formal search was carried out in February 2020 using the finalised search strategy (Appendix 2). This used a combination of free text search terms and subject headings. Medline, Embase, CINAHL and Cochrane databases were searched. Like Smith et al (2016), we limited our search strategy from 1990 onwards. All references and citations of the included papers were searched but no further papers were identified.

6.2.2 Paper Screening

Other than the types of studies included the inclusion and exclusion criteria were broadly similar to the Cochrane review of multimorbidity interventions (Susan M. Smith et al., 2016). Due to work in this area varying in quality the review chose to focus on high quality interventions evaluated by a randomised trial, not simply service redesign. The inclusion and exclusion criteria are summarised in table 6.1.

Table 6-1 Table demonstrating Inclusion and Exclusion Criteria for papers within the review.

Inclusion Criteria	
Types of Studies	• Qualitative studies exploring participant experience of primary care based multimorbidity interventions • Mixed methods evaluation studies that include qualitative work that is reported in the paper
Participants	• Any geographical location • Adults (aged over 16) • Participants in randomised trials of a primary or community care interventions targeting multimorbidity management (two or more long-term conditions)
Types of Intervention	Interventions that are: • Specifically aimed at multimorbidity • Community or primary care-based, delivered by primary care staff (definition from the Cochrane review: *"those available to treat all common conditions in all age groups and have an ongoing relationship with their patients"* (Susan M. Smith et al., 2016) • Where multimorbidity is confirmed by the recording of LTCs for each participant • Has been, or in the process of being, evaluated by a randomised trial.
Exclusion Criteria	
Types of Studies	• Non-Randomised Trials • Other experimental studies • Before and after studies • Cohort studies • Cross-sectional studies • Observational studies • Discussion papers • Literature reviews • Single case studies/case reports • Guidelines • Policy statements and letters.
Participants	• Children (aged under 16)
Types of Intervention	Interventions • Aimed at patients with comorbid conditions, but only at one condition, and not addressing the full extent of the multimorbidity, e.g., an intervention targeting patients with both diabetes and depression, where the intervention itself only targeted depression would not be included • Targeting professionals with no clinical element targeting patients with multimorbidity • Where multimorbidity is assumed but not confirmed/recorded, for each participant

Distiller software, software designed to support screening and data extraction for systematic reviews, was used to facilitate the screening process (Distiller, 2023). There were two screening stages: stage one title and abstract screening, stage two full text screening. Articles were included or excluded in line with pre-defined inclusion and exclusion criteria (Table 6.1). Two reviewers independently screened each paper at every stage, and papers were only excluded if both agreed; disagreements were resolved through discussion with a third reviewer.

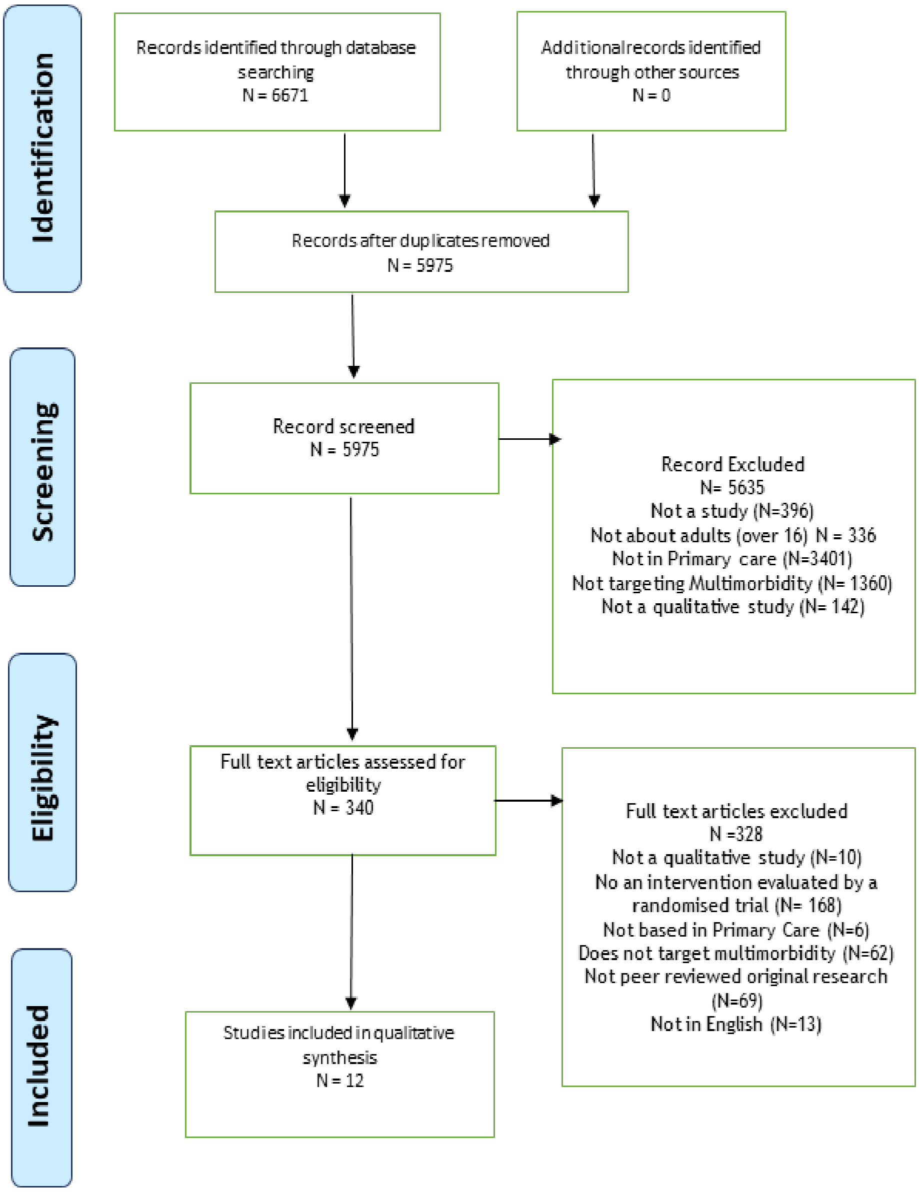
6.2.3 Data Extraction and Quality Appraisal

Initial data extraction was carried out using a pre-defined template (Appendix 3) to summarise baseline characteristics of each paper and collect broad, initial information on treatment burden, capacity, social context, and self-management.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) tool (Tong et al., 2007) was used to quality appraise identified papers. This tool was applied to each paper by one of the screening reviewers; each appraiser writing a summary of their thoughts of overall paper quality. As previously discussed, due to the nature of qualitative work even work appraised of being of poorer quality may yield valuable insights. Therefore, no paper was excluded based on quality appraisal, rather the results of the appraisal informed interpretation during the analysis.

Our search identified 6671 papers, with no further papers identified via reference searching. The initial key papers identified in the scoping search were all picked up via the search strategy. Once duplicates were removed 5974 papers were eligible for screening and 12 papers were identified as meeting our inclusion criteria. The PRISMA flow chart summarising this is shown in Figure 6.1.

Figure 6-1 PRISMA chart of Review Search



After initial data extraction and quality appraisal the data extraction process for the meta-ethnography followed the eMERGE guidelines for reporting of meta-ethnography (France et al., 2019).

6.2.4 Data Synthesis – Meta-ethnography

Chapter 5 discusses the development and principles underlying meta-ethnography in detail. Initially each study was read and re-read to allow immersion in the data, with emerging metaphors identified. Microsoft excel was used to categorise each emerging metaphor (and any other relevant data) for each paper.

The metaphors were then translated into one another by comparing metaphors from each paper with the metaphors from the others. Attention was paid to similarities and differences between metaphors, as well as how context influenced this. This was an iterative approach: as new metaphors emerged it required returning to previous papers to explore whether new findings revealed new insights. The findings from this translation process resulted in shared themes across the papers. Throughout the translation process emerging concepts were discussed with the project supervisors to ensure fidelity to the literature.

As data emerged, there was also reflection on what type of synthesis would be appropriate. A reciprocal synthesis was conducted for most of the themes, with a smaller refutational synthesis covering one theme - person-centred care - where some of the metaphors in one study were refutational. The synthesis involved summarising the comparison of the themes between the papers and this process generated new themes, what meta-ethnography methodology terms third order constructs. As potential third order constructs emerged Microsoft excel was again used to cross-tabulate relevant data for each potential construct. This allowed the validity of potential Third Order Constructs to be examined. Through this process clear definitions for the third order constructs emerged that were rooted in the original data from the papers. Once the third order construct definitions were established the relationship between them was examined which allowed a line of argument synthesis.

6.3 Results

6.3.1 Included studies

One key finding was the paucity of identified literature with only 12 papers meeting our inclusion criteria; two of these were from the same intervention (so 11 interventions in all). Of the papers identified most were undertaken in North America or Europe (USA 2, Canada 2, UK 4, mainland Europe 2) with one in Rural China. Four of the interventions were person facing (focusing on education or self-management) with the remaining studies predominantly involving organisational change. Five targeted specific groups of conditions (Blixen et al., 2015, Knowles et al., 2015, Li et al., 2019, Middlemass et al., 2017, Sussman et al., 2016) while the rest targeted multimorbidity (two or more LTCs).

The degree and depth of qualitative analysis varied considerably. Five of the papers used mixed methodologies (Edlind et al., 2018, Ford et al., 2019, Mann et al., 2018, Mann et al., 2019, Sussman et al., 2016); of note the qualitative aspect of these mixed methods papers often demonstrated high rigour. Of the remaining trials five used in-depth interviews (Blixen et al., 2015, Boeckxstaens et al., 2020, Knowles et al., 2015, McCallum M et al., 2019, Middlemass et al., 2017), one telephone interviews (Zechmann et al., 2019) and one focus groups to explore participant experience (Li et al., 2019).

There was also variation in whose opinions were sought: three studies only interviewed practitioners (Blixen et al., 2015, Boeckxstaens et al., 2020, Li et al., 2019), five interviewed both practitioners and patients (although most of these focused on patient experience of intervention implementation or specific intervention components) (Edlind et al., 2018, Ford et al., 2019, Knowles et al., 2015, Mann et al., 2018, Mann et al., 2019). Three studies focused only on patient experience (McCallum M et al., 2019, Middlemass et al., 2017, Zechmann et al., 2019), with the final study interviewing friends and family of patients who had participated in the intervention to understand their experience (Knowles et al., 2015, Sussman et al., 2016). Only three studies actively explored the experience of participants who either did not complete the intervention, or who did not feel they benefited from it (Edlind et al., 2018, McCallum M et al., 2019, Zechmann et al., 2019). One further study did target people who did not complete the intervention in their sampling but did not explore how this influenced experience in their analysis (Knowles et al., 2015).

Table 6-2 Table summarising key characteristics of identified papers

Paper	Year	Intervention	Location	Target Population	Methodology	Participants	
						Patients	**Practitioners**
(Blixen et al., 2015)	2015	Targeted Training in Illness Management (TTIM) a group based educational programme, with peer educators, for people with serious mental illness and Diabetes.	Ohio, Cleveland, USA	Adults with Serious Mental Illness and Diabetes	In-depth interviews with the Peer Educators to understand their experience and explore key learning to better use of these roles in future interventions		Explored the experience of the training and implementation of the intervention from the perspective of the peer educators
(Boeckxstaens et al., 2020)	2020	Bringing together primary and secondary care professionals for MDT patient reviews	Toronto, Canada	Adults (18-80) with three or more long-term conditions	In-depth interviews with physicians taking part in interventions		Physicians who took part in the MDT meetings
(Edlind et al., 2018)	2018	IMPaCT: Community Health Workers supported participants to create and implement action plans targeting chronic disease goals over six months encouraging goal orientated change with regular follow up	High poverty region in USA	Adults with two or more chronic conditions living in the area the intervention targeted	Mixed method evaluation of intervention exploring factors that influenced engagement with the intervention. Qualitative component was in-depth interviews with participants and community health workers	10 responders and 10 non-responders interviewed	All the community health workers interviewed
(Ford et al., 2019)	2019	GPs were trained in delivering goal-setting consultations. Participants had an initial 20-minute consultation, with a follow up six-month consultation to review goals	East of England	Adults with two or more long term conditions at risk of unplanned hospital admission	Mixed method feasibility study including quantitative and health economic data collection. Qualitative component was focus groups (and in-depth interviews for those who couldn't make the group) with GPs and Participants	One focus group and two in-depth interviews with participants	One Practitioner focus group (Separate from participant group) and one interview.

(Knowles et al., 2015)	2015	COINCIDE trial that sought to provide mental health support to patients with long-term conditions by embedding a psychological wellbeing practitioner into local general practices	Northwest England	Depression and at least one of either Diabetes or Chronic Heart Disease	In depth interviews of participants and practitioners	31 participants (mix of those who did and did not complete intervention, but not analysed separately)	11 Psychological Wellbeing Practitioners, 12 Practice nurses and 7 GPs
(Li et al., 2019)	2019	COACH study: Supportive training for village doctors to screen then treat elderly people for both depression and hypertension. Participants identified by screening also received regular visits by an aging worker who focused on eliciting and managing social concerns. Regular discussion of patients with supervision from consultant psychiatrist	Rural China	Adults over 60 with both depression and hypertension living in participating villages	Qualitative review of participant experience of the trial		Five focus groups made up of each group of practitioners (village doctors, aging workers, and psychiatrists)
(Mann et al., 2018) (Review 3D template)	2018	3D intervention (Dimensions of Health, Drugs and Depression) involved a biannual two-part 3D multimorbidity review: face to face review by a practice nurse where patient agenda agreed,	UK	Adults with three or more long term conditions	Observations and recordings (video and audio) of patient reviews, interviews with patients and clinicians and focus groups with patients used to evaluate the use of the computer template.	Interviews and focus groups with patients discussing the template, observations of clinical reviews	Interviews with practice nurses and GPs who had participated, as well as review of consultations.

(Mann et al., 2019) (Evaluation 3D)		a remote review of medication by a pharmacist followed by a second review with a GP			Process evaluation of the intervention used in depth interviews with participants and practitioners, observation of reviews and focus groups patients	Focus groups with patients discussing the experience of the intervention, follow up interviews discussing the reviews and observations of clinical reviews	Interviews with practice nurses and GPs who had participated, as well as review of consultations.
(McCallum M et al., 2019)	2019	CARE Plus: whole system intervention aiming to improve wellbeing and support goal focused care. It did this by providing resource to allow longer patient reviews, training for practitioners in holistic assessment and goal setting and, providing self-help packs for participants.	Areas of high SED in Scotland	30-65 with two or more long term conditions and whose “GP thought might benefit”	Analysis of in-depth interviews of participants, with a framework analysis using self-determination theory.	14 participants underwent in-depth interview 8 at 3 months into intervention, 6 at 12 months.	
(Middlemass et al., 2017)	2017	Installation of telemonitoring equipment, with clinical alerts sent to GPs if readings dropped below a pre-agreed level. Aimed to pick up early deterioration and reduce hospital admission	Multi-centre across mainland Europe	Over 60 with COPD and either ischaemic heart disease or heart failure	Nested qualitative evaluation of multi-centre trial. In depth qualitative interviews shortly after installation and at the end (or withdrawal) from the trial.	In-depth interviews to understand participant experience	

(Sussman et al., 2016)	2016	This intervention examined whether telephone-based support for a toolkit of information and CBT based information in AV and written format influenced outcomes compared to the toolkit alone	Montreal, Canada	Over 40 with at least one doctor diagnosed physical health condition and depression	Mixed method evaluation of role of friends and family in experience of intervention. In-depth telephone interviews with friends and family participants identified as being helpful by participants	10 friends and family of participants, interviewed 6-12 months after the trial	
(Zechmann et al., 2019)	2019	GPs used an algorithm to go through participants medications and where appropriate GP offered to make medication changes (87/128 reviews carried out advised at least one medication change). Participants could then choose whether to do so.	Northern Switzerland	Over 60 and taking over five medications a day	Telephone qualitative interviews carried out targeting participants who had refused GP's medication suggestion. Questions based on previous qualitative work looking at deprescribing.	22 out of 87 participants did not pursue GP recommendation, 19 interviewed.	

6.3.2 Quality Appraisal

The results of the COREQ checklist for each paper is summarised in Table 6.3.

Table 6-3 Table summarising the key findings from the Quality Appraisal for the included articles.

Papers	Summary of findings from CoreQ checklist(Tong et al., 2007)
Blixen et al (2015)	
Research Team and Reflexivity	Background of the research team and the study were well described.
Study Design	Study methodology well described; no information given as to whether field notes were made at the time, or whether data saturation was reached. Transcripts were not returned to participants for comment/correction
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants and no minor themes were discussed.
Boeckxstaens et al (2020)	
Research Team and Reflexivity	Key characteristics and backgrounds of the research team, and their relationship with the participants were reported.
Study Design	A specific theoretical framework was not mentioned regarding data analysis; however, data analysis method was clearly documented and follows standard iterative qualitative processes. Participant selection, and key characteristics described, and authors describe a purposive sample was taken of one of the TIPS team. No information on whether anyone refused interview. Data collection is well described, although no information on a topic guide or prompts given. Transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants and no minor themes were discussed.
Edlind et al (2018)	
Research Team and Reflexivity	Study reports they used “trained interviewers”, and that they were independent of the study, no further information given on background.
Study Design	Study design well described with clear theoretical framework. Transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants and no minor themes were discussed.
Ford et al (2019)	
Research Team and Reflexivity	Key characteristics and backgrounds of the research team, and their relationship with the participants were reported.

Study Design	Study design broadly well described, although data analysis methodology was not clear. The authors used a framework analysis based around acceptability, not clear if other themes emerged. Not clear if a topic guide was used for interviews, or whether data saturation occurred.
Analysis and Findings	Study findings were reported clearly with the criteria suggested in the checklist. Feedback on findings were not given to participants, although two members of a PPI group reviewed manuscripts and some of the findings. No minor themes were discussed.
Knowles et al (2015)	
Research Team and Reflexivity	Team members who carried out the interviews and analysis are identified in the manuscript but other than their affiliated institution little information is given about their background. Those who analysed the transcripts did so prior to the results of the trial and so were blinded to the trial outcome.
Study Design	Study design is well described, it is not clear if field notes were taken at the interviews. Transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants.
Li et al (2019)	
Research Team and Reflexivity	Little information given about the background of the team members involved in recruiting and interviewing patients.
Study Design	Study design well described with a clear theoretical underpinning. Sampling strategy not explicitly described and no information on how many people refused to participate. Data saturation not mentioned, transcripts were not returned to participants for comments.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants and no minor themes were discussed.
Mann et al (2018) (Review 3D template)	
Research Team and Reflexivity	Background of team members described, and potential bias of main data collector discussed.
Study Design	Study was part of large evaluation of the trial and underpinned by a process evaluation framework for cluster randomised trials, rather than qualitative methodology. The methodology used for this process evaluation is well described. No information on how many people refused to take part in qualitative interviews, and no discussion of data saturation. Transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants, although some of the transcripts were double coded by members from a PPI group
Mann et al (2019) (Evaluation 3D)	
Research Team and Reflexivity	In-depth description of the backgrounds, and potential bias, of team members who collected and analysed the data.
Study Design	Study was part of large evaluation of the trial, underpinned by process evaluation framework for cluster randomised trials, rather than qualitative methodology. Methodology well described. No information on whether anyone refused interview but rationale for purposive sampling well explained. Transcripts were not returned to participants for comment/correction.

Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants, although some of the transcripts were double coded by members from a PPI group
McCallum et al (2019)	
Research Team and Reflexivity	Background of data collector, and team who analysed data described. Not clear if pre-existing relationship with participants
Study Design	Study design well described, no information given on numbers who refused to participate, though noted in text there were some problems with recruitment for interviews. Transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants (although this was a secondary analysis).
Middllemass et al (2017)	
Research Team and Reflexivity	Background of research team explained, no discussion of potential bias, or the connection of the interviewers to the trial.
Study Design	This was a nested qualitative evaluation inside a wider RCT with a framework applied to the transcripts. There was no information on key demographics of the people interviewed, data saturation was not discussed. Transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants and there was no discussion of themes that fell out with framework used.
Sussman et al (2016)	
Research Team and Reflexivity	Job description of researchers involved in collecting and analysing data briefly described no information on further potential biases discussed
Study Design	Study design well described, although no mention if data saturation reached. Transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants
Zechmann et al (2019)	
Research Team and Reflexivity	Information on member of team involved in collection and analyses, and that they were already involved in the study. No discussion of potential bias.
Study Design	Study design well described; transcripts were not returned to participants for comment/correction.
Analysis and Findings	Study findings were reported clearly in accordance with the criteria suggested in the checklist. Feedback on findings were not given to participants

All the papers selected were of reasonable quality, although the depth and rigour of the qualitative methodology varied significantly. Where quality was most poorly demonstrated it tended to be in the domain of “Research team and Reflexivity” with information regarding background, experience and potential bias of the research team often limited. Where team members were described, it was often in vague terms (such as trained interviewer, qualitative researcher), and the relationship between team members and study participants was frequently unclear. Some further information regarding research team standpoint, and background, could be gleaned from the wider paper, but this involved assumptions on the part of the reviewer. The worldview, experience and potential bias of the researchers is important information for interpreting results. Few papers discussed potential bias within the research team, though when explicitly stated this was helpful (Mann et al., 2018, Mann et al., 2019). The health science context may explain the lack of detailed team information as many researchers have a mixed methods rather than qualitative background.

Several studies did not report on data saturation, which meant the reviewers could not determine if there were still potential emerging themes. In addition, when minor themes were not discussed it was unclear if this was because there were none, or if these had not been reported in the analysis. None of the studies gave transcripts back to participants to check, nor did they discuss results with participants (although one study did have high PPI involvement in the analysis process). However, although a checklist criterion, there remains debate regarding the value of returning transcripts, or results, to participants (Robert Emerson and Pollner, 2008, Robert M. Emerson et al., 2001, Rock, 2001). It did not influence overall quality significantly for any of the papers. This highlights the importance of not using COREQ as a simple checklist but rather as a tool to examine quality in context.

6.3.3 Analysis

The first key finding was the paucity of literature on participant experience of multimorbidity interventions, much of which focused on practitioner experience, or intervention implementation. Very few directly explored the experience of participants who had not engaged or benefited. This is critical because insights derived from studies exploring this issue in-depth, revealed important and, at times, unexpected themes. These could be important to improve efficacy of existing interventions as well as informing future intervention.

> "Yet failure and nonresponse are understudied. Quantitative analyses examining nonresponse are often unrevealing, likely because we are not measuring the right baseline variables. We should measure not only demographic, but psychological characteristics (e.g., grit, response to failure, or coping style) in intervention trials. Understanding predictors of nonresponse could inform targeting of interventions for maximal benefit. Alternately, interventions could be modified to better serve would be non-responders; for instance based on these findings, the study team is planning to train IMPaCT CHWs [community health workers] on positive affect induction and attribution retraining."
>
> (Edlind et al., 2018)

While participants welcomed components within interventions that allowed them to explore concerns and priorities it is not clear whether identifying these led to any discernible change. Though few papers explored participants response to interventions those that did suggest that wider personality, and social, factors are all barriers to engaging in interventions, and a one size fits all approach is not effective for certain patients.

6.3.4 Development of Third Order Constructs

The meta-ethnography process revealed multiple metaphors and through the translation process several third order constructs emerged. A worked example illustrating how one of these third order constructs ("Right person, Right time") was developed is described in Table 6.4.

Table 6-4 Table demonstrating how different metaphors coalesced to produce the theme "Right Person, Right Time"

Paper	Themes emerging from paper (Second Order Constructs)	Illustrative Quotes	Reciprocal Themes	"Right Person Right Time" (Third Order Construct Definition)
Blixen(Blixen et al., 2015)	Peer educators relatable, same lived experience as participants.	*"You kind of know that you're not more than and not less than; everybody is kind of on an equal footing"*	New role recruited from "target community"	Interventions that had a variety of practitioners working as a team appeared to be effective in meeting patient's concerns while also addressing ongoing medical issues. What appeared key was access to the right person with the right skills, at the right time. Several interventions created new lay roles that appeared to be particularly effective at addressing, or simply just acknowledging participants wider social and personal concerns. When part of a wider team these roles could support participant social concerns to be explored and addressed which allowed clinical practitioners to focus on medical concerns. These roles were employed across different countries and communities; it appeared important that these roles were either "from" the target community, or had similar experiences (e.g., having the same medical conditions)
	Peer Educators not experts, had a different supportive role	*"PEs[Peer Educators] were not envisioned as 'experts' or the perfect example of how to manage SMI [Serious Mental Illness] and DM[Diabetes]. Instead, it was stressed that we learn as much through mistakes as successes, and PEs were used as experiential experts on what worked/did not work for them so that the group could learn together and in acknowledging that learning is a continuous process"*	New "lay" role	
	Supportive role appeared important in increasing confidence and self-efficacy	*'I felt more confidence, maybe not more confidence, but more competent. The things that I was thinking about are not way out of left field, other people are having the same thoughts or same concerns. So I felt more in step with the program, with the manual and what we were expected to do and what others were doing'. Respondent 3*	Focus "more than medical", by addressing concerns enabled participants to focus on clinical aspects of programme Positive benefit to participants from managing social and personal concerns	
Boeckxstaens	Multidisciplinary team used to meet different identified needs	*"There's an added value by far … because [the patients] have multiple things going on, social, functional, cognitive, medical. It really is useful having that full interdisciplinary team for these particular patients"*	Multimorbidity complex: one person cannot meet all needs	
Edlind	Community Health Workers (CHWs) recruited from the	"CHWs were recruited by circulating job descriptions through a network of community-based organizations (e.g.,	New role recruited from "target community"	

	same community being targeted	neighbourhood associations, churches). Job applicants were screened through group and individual interviews and employer reference checks to identify individuals who were good listeners, non-judgemental and reliable”	New “lay” role	
	Flexible approach: focus on changing one aspect of chronic disease behaviour but CHWs also discussed and supported wider social factors, and adjusted approach based on this.	Interestingly, when CHWs adjusted their approach and deliberately stopped discussing self-monitoring or health goals, patients sometimes became re-engaged. As told from a CHW’s perspective: “*She was avoiding my calls because her sugars were high. So I left messages purely to make her smile. She began to call me…checking her sugars, without me asking! [CHW]*”	Focus “more than medical”, by addressing concerns enabled participants to focus on clinical aspects of programme Positive benefit to participants from managing social and personal concerns	
Knowles	Aim of intervention to integrate care, yet patients and professionals valued a degree of separation. Recognition that different professionals had different skills and expertise for specific patient needs.	PT20: *“its two different things. I wouldn’t go to [PN name] and start crying my eyes out and saying I miss my dad and all that. She controls my medication. That [the mental health aspect] was emotional…Separate. Absolutely separate… I don’t think you’re ever going to get one person doing all that.”*	Multimorbidity complex: one person cannot meet all needs	
Li	Value of important but different skills of the professional roles and the benefit when they all complement	VDs, AWs, and psychiatrists all said that each of the team members had unique strengths. Specifically, they perceived that VDs had medical knowledge and skills to care for patients, AWs provided organizational and logistical assistance, and psychiatrists offered professional guidance and consultation.	Multimorbidity complex: one person cannot meet all needs	

	Aging worker (AW) role – existing role in the village by people accepted by the elders	Even though AWs were not medical professionals, they were seen as representing the support of village leadership, which was vitally important in getting collaboration of patients. A psychiatrist said: We certainly need the support of village leaders…The village leaders have authority and credibility, and the villagers listen to them. When we need to see the patients, we contact the AW. (PSY E)	New role recruited from "target community" New "lay" role	
	Flexible AW role: flexible remit, target whole family, able to support any identified social concerns, key to improving mental well-being.	VDs and AWs felt that older patients' family support increased as a result of the COACH intervention, due partly to reduced depressive symptoms and partly to the education of their family members. As explained by an AW and a VD: *I ask adult children of older patients to visit their parents as frequently as possible. Older people need care and concern from their children more than anything. It's more effective than medicine. So we talk to the adult children. (AW1B)* *Due to [the older person's] depressive symptoms, family members find it hard to communicate with them. After our intervention, their mood elevates and the communication with family members is improved. The whole family atmosphere is much better. I feel very good seeing that.* (VD2A)	Focus "more than medical", by addressing concerns enabled participants to focus on clinical aspects of programme	

The agreement of metaphors when translated across different studies indicated a reciprocal translation was appropriate. The one refutional translation was related to person-centred care. There was a tension between several studies which had an implicit expectation that PCC alone would improve intervention engagement, and one study that showed that participants who felt secure in their relationship with their GP also felt more empowered to reject the intervention. This is discussed in more detail in the section on patient centred care.

As the third order constructs emerged, a description was developed for each, discussed in detail below. After examining the relationship between these constructs a line of argument synthesis was developed. Ther third order constructs coalesced under two main concepts: *"Patient Centred Care?"* and *"Intervention Design*".

6.3.6 Person Centred Care (PCC)?

Many of the interventions discussed, or described themselves, as person centred but the definition was often practitioner defined or restricted to specific components of the intervention. Most of the studies focused on practitioner experience; where participants were interviewed it was often within the context of implementation of the intervention rather than a wider exploration of their experience. For example, Middlemass et al (2017) asked questions centred around installation of technology and how it had functioned. Several interventions purported to be person centred, however the definition of this was frequently practitioner defined.

> GPs described the goal-setting consultations as '*more patient-centred'* and reflected on the consultation's '*therapeutic powers*' (GP10) compared with day-to-day general practice, which GPs felt could be dominated by '*box-ticking*' and '*target driven*'(GP018) medicine.
>
> (Ford et al., 2019)

Without understanding participant experience, or how (and by whom) PCC is defined, it is hard to know whether these interventions met their aims, or indeed what was important to participants.

Practitioner relationship did appear to be important in enabling participants to set the agenda, or articulate key concerns or priorities. A positive relationship alone did not equate to participant enablement, but a negative relationship may have prevented it.

> For both these participants, the pre-existing [negative] relationship with their practitioner prevented them from being honest about their problems or following advice during CARE Plus consultations.
>
> (McCallum M et al., 2019)

6.3.6.1 Intervention enables Person-centred Care

Intervention components attempting to increase person-centredness appeared to be partially effective. There was some evidence that intervention structures could shift care to more PCC in comparison to usual.

> However, most clinicians highly valued the enquiry about the patient's agenda and saw it as novel. Some identified unmet health needs through patients revealing previously unmentioned symptoms, leading to new diagnoses, for example, melanoma, heart failure, and hip osteoarthritis
>
> (Mann et al., 2018)

Where this happened, it was valued by participants and practitioners:

> Patients' comments on being asked about all their concerns were very positive. They felt heard, and they valued the comprehensive, thorough, and holistic nature of the review. This gave some a sense of empowerment:
> '*This gives me that kind of overview where you think "well I'm the person that's getting attended here, it's not what this GP wants or thinks it's what … my needs are"* (Lovall, Pt7, Focus Group)
>
> (Mann et al., 2018)

> *I felt almost as if I was trying to put on a different hat, you know, trying not to constantly interrupt them or to sort of sway them in any way, I was trying to give them the opportunity to just say what they wanted to say and set any goal that they wanted to and I, and it made me reflect on actually what I do during the day to day when I've got ten minutes with a patient and I'm very aware of the sort of pressure of, oh I've got to do a medication review and I've got to do this and oh no, their cholesterol's now 7 and oh gosh I've, have my*

> *colleagues already spoke to them about this and are they aware of X, Y and Z and actually it was quite nice in a way just take a step back and think, um I don't have to do that with this consultation, let's see what happens when the patient has more control over it.* (GP025)
>
> (Ford et al., 2019)

Components of interventions that appeared effective at shifting practitioner practice towards person-centredness included longer consultations focused on participants' agendas (Ford et al., 2019, McCallum M et al., 2019) asking open questions at the start of consultations (Mann et al., 2018, Mann et al., 2019) or using a lay role to explore, and support, participant's social context and current priorities (Blixen et al., 2015, Edlind et al., 2018, Li et al., 2019)

6.3.6.2 Circumstances force reversion

However, while interventions appeared effective in at least partially shifting practice, other pressures meant practitioners, even if they wished to practice in a more person-centred way, almost always reverted to usual care. The main reasons for this were professional identity, clinical concern, and wider structural restrictions (e.g., lack of referral pathways or supports, or time pressures meaning clinicians could not explore raised issues in adequate depth).

Professional Identity

Some practitioners felt frustration at being expected to manage things they deemed not medical concerns:

> Several clinicians, especially GPs, questioned the appropriateness of some concerns raised by patients, seeing them as less important than the LTC(s) under review and others expressed frustration over having to revisit problems that could not be resolved: '*She had a load of things she wanted to talk about which were irrelevant to her …chronic disease management … it was "I want to talk about the numbness in my feet I have had for 20 years."*' (Davy, GP1).
>
> Mann et al (2019)

Clinical Concern

In addition, while acknowledging the importance of the concerns raised by participants, practitioners also described a strong duty of care to manage, prevent and treat disease. Clinical concern, particularly regarding deteriorating medical results meant that they felt compelled to focus on treating disease (and this was generally physical) even if that was not the patient's priority.

> *"I think if you asked a patient what their agenda was a lot of patients would say, yes, the depression is outweighing everything else, but obviously for the healthcare point of view sometimes you look at results, and you have to put it holistically with the patient, you know, and think, golly, these results are diabolical, we've got to get your diabetes on track, and then the depression would take a second seat I think really"* PN04

(Knowles et al., 2015)

Wider system

The external pressures from the wider systems meant a lack of resource or time to allow practitioners to practice in a truly person-centred way even if they wanted to. For example, several interventions prompted exploration of participant's priorities but then provided no resource or support for participant or practitioner:

> Difficulties with arranging appointments reinforced practices' initial fears that the time demand and workload of implementing the 3D intervention would be too great.

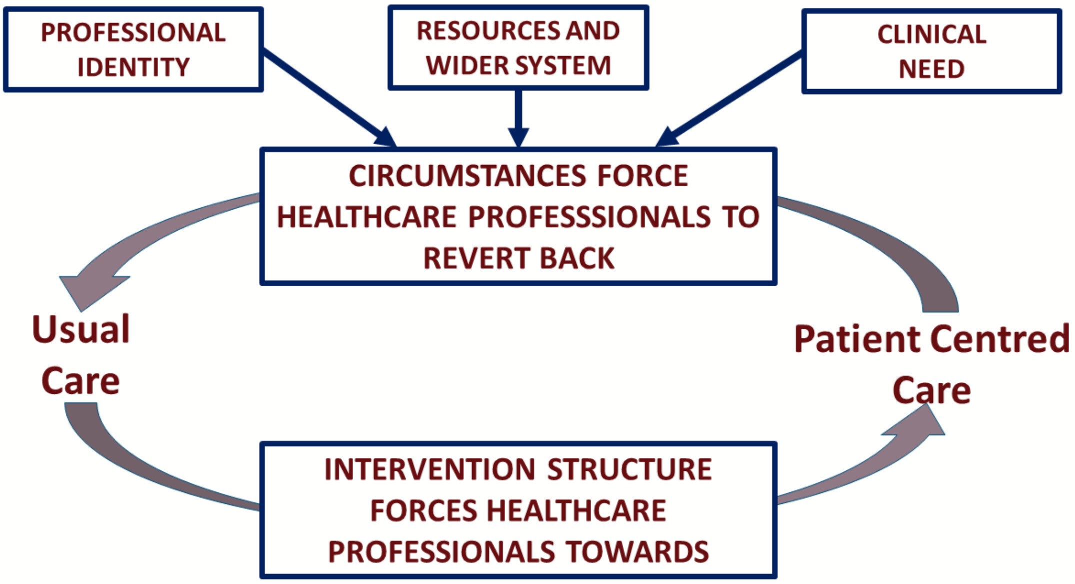
(Mann et al., 2019)

Furthermore, interventions that trained practitioners in goal setting, or creating consultations around the participant agenda, appeared to have an implicit expectation this alone would improve health outcomes. However, when Zechmann et al (2019) explored the experience of participants who decided not to take up a deprescribing intervention, they found several of their participants had a very secure relationship with their GP. This meant they were happy to refuse an offer of treatment without concern their relationship or treatment would be compromised.

> Trust could even be an enabler for choosing not to pursue the offer, as patients may feel confident that their GPs are open-minded for listening to their opinions and concerns. Thus, patients with a high level of trust in their GPs even may feel encouraged not to pursue the offer. A decision not to pursue the GP's offer, is meeting the spirit of SDM [shared decision making] and therefore is a positive outcome.
>
> (Zechmann et al., 2019)

This suggests providing more person-centred care and improving uptake of evidence-based treatment may be in tension. At the very least it suggests improving specific health outcomes for people living with multimorbidity will require more than simply making care more person-centred. However, as discussed, with limited participant voice, it is not clear whether attempts to make care more person-centred were experienced as that. Also, participants tended to prioritise managing social and personal concerns. If the interventions had continued for longer there may have been a shift to tackle medical issues once more pressing social and personal concerns were addressed. The "Person-centred Care?" construct is summarised in Figure 6.2.

Figure 6-2 Third Order Construct of "Person Centred Care?": summarising how both an intervention, and the wider system, influence healthcare professionals' provision of Person-Centred Care.



6.3.7 Intervention Design

The remaining third order constructs converged under the umbrella of intervention design. The analysis suggests that there are two important underlying principles required for an intervention to be effective: structure (evidence-based fidelity) and flexibility (ability to adapt to participant context). There is a fundamental tension between these concepts; interventions that manage this tension and integrate flexibility yet permit fidelity to the evidence base may be more efficacious at engaging participants and improving outcomes.

6.3.7.1 Structure:

An intervention seeks to “do” something, that is reproducible and broadly similar for each participant. Two important aspects required to achieve this emerged: strong theoretical underpinning and practitioner buy in.

Theoretical Underpinning

The importance of an evidence base and, where possible, theory in intervention design is well-established (Skivington et al., 2021, Wight et al., 2016). All the interventions mentioned some theoretical underpinning in the intervention design. However, the extent to which this theory was integrated, or that authors described how and why this intervention would produce the results expected, varied significantly.

Practitioner Buy In

The degree of training (and potentially more critically) supervision practitioners received varied considerably. There was evidence that high levels of training and/or supervision allowed practitioners to be flexible in applying the intervention, while still sticking to the underlying evidence base. Conversely, where this did not occur practitioners often did not fully understand the theory behind what they had been asked to do, or did not apply it, meaning the new way of working the intervention set out to measure may not have differed from usual care:

> Some clinicians felt that the training provided by the trial team was insufficient to enhance skills required for agenda setting and especially collaborative action-planning.
> *“I think some kind of communication training …would have been useful…there was a little bit about goal setting and confidence skills but there was no real practical element to it so in some ways you’re*

> *testing what we already do but in a different context.*" [Interview Lovell GP1]
>
> (Mann et al., 2018)

6.3.7.2 Flexibility:

Multimorbidity interventions do not take place in "perfect" conditions but in the real world where external factors out with the intervention will have impact. Participants circumstances and life experiences were complex and varied; to be able to adapt to these circumstances' interventions needed a degree of flexibility. This meant recognising "one size doesn't fit all" and that people need the "right person at the right time".

One size doesn't fit all

Even in interventions felt to be successful practitioners and participant recognised the intervention would not work for everyone. Where studies explored experience of those who did not engage or benefit it appeared personality factors (resilience, preference for supportive vs goal orientated accountability) were particularly important in determining whether someone engaged or benefited.

> Responders seemed to be motivated by failure and went on to "work even harder" with their CHW on health behaviour change, ultimately improving chronic disease control. Non-responders appeared discouraged by failure and avoided their CHWs. Interestingly, these patients may have been reengaged when CHWs stopped focusing on the "numbers" and provided pure emotional support.
>
> (Edlind et al., 2018)

The role of family and friends was also important, particularly how the participant responded to lack of, or negative, support:

> In contrast, the slight improvement group all described having more limited social support, with many relationships mentioned appearing to be unsupportive or even obstructive:
>
> *"my daughter's out at work all day right enough but sometimes me and her clash as well and that causes anxiety and that, all 'cause me and her are sometimes fighting and arguing and things, and that*

> *kinda causes anxiety'. But it's only because she's really the only other adult that I see apart from sometimes if I go round to my mammy. I don't see any other adults"* Participant 5 (female, 51)
>
> (McCallum M et al., 2019)

Social isolation and the death of a close relative had a negative impact often resulting in non-engagement. It is likely that other personal and social factors are important, but these have not been explored.

Right person at the Right Time

Participants experiencing multimorbidity have complex needs and required a variety of supports and engagement of several practitioners; moreover, such support required integration. Ensuring flexibility in access to the right person at the right time is important in the management of people experiencing multimorbidity.

> PN10: *We see patients in primary care and try to be holistic, [but] we have to realise that we do have limitations in what care we can provide and sharing patient care with other professionals…You have to realise that you have limitations and there comes a point where there are other better qualified people who are better able to care for that patient.*
>
> (Knowles et al., 2015)

Introducing flexibility to support these concerns (either by using lay roles with a wide social remit, or in the way consultations were structured) appeared to be of value. The lay roles could be effective at addressing, or simply just acknowledging, participants wider social and personal concerns. When part of a wider team these roles supported exploring and addressing participant social concerns which allowed clinical practitioners to focus on medical concerns. These roles were recruited "from" the same community, or had similar experiences (e.g., the same medical conditions).

> There was a consensus among the team members that a team approach made good sense, as illustrated by a VD [village doctor]: Since psychiatrists have more professional knowledge and AWs [aging workers] know much more about the family and living condition of patients than we do, working as a team can help us to have a whole-person understanding of the patient. (VD2)

> (Li et al., 2019)

6.3.7.3 Managing the Tension

Inadvertent Flexibility

Managing the tension between structure and flexibility was important. Interventions which included some flexibility (by including flexible components, or a lay worker role with a broad remit) appeared to be effective. Of note this flexibility was often inadvertent: either participants adapting the intervention to what worked for them, or practitioners being flexible in how they applied the principles of the intervention. There is some evidence that where this occurred it enhanced participant engagement.

> Interestingly, when CHWs adjusted their approach and deliberately stopped discussing self-monitoring or health goals, patients sometimes became re-engaged. As told from a CHW's perspective: *"She was avoiding my calls because her sugars were high. So I left messages purely to make her smile. She began to call me…checking her sugars, without me asking! [CHW]"*
>
> (Edlind et al., 2018)

Preparation for Failure

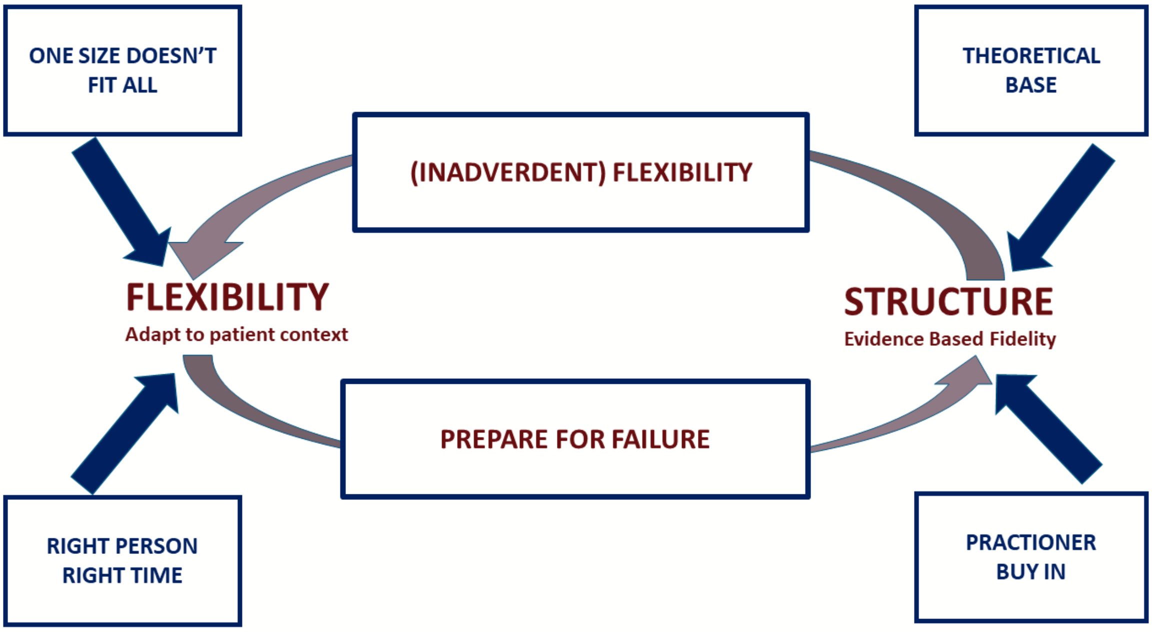
There was a paucity of evidence exploring the reasons why participants did not engage in, or complete, an intervention – this is a critical omission. We should "prepare for failure" as at least some participants will struggle to engage. Building in evaluation of participant experience to understand and explore who the intervention works for, in what context and why may result in higher engagement and allow modification of existing interventions to improve efficacy.

> Understanding predictors of nonresponse could inform targeting of interventions for maximal benefit. Alternately, interventions could be modified to better serve would be nonresponders; for instance, based on these findings, the study team is planning to train IMPaCT CHWs[community health workers] on positive affect induction and attribution retraining. Perhaps in the future, CHWs will be able to help patients face the failures that are an inevitable part of behavior change.

(Edlind et al., 2018)

The relationship that emerged through exploration of the intervention design third order constructs is summarised in Figure 6.3.

Figure 6-3 Third order construct of Intervention Design: demonstrating how Structure and Flexibility (sometimes inadvertent) relate to one another.



6.4 Conclusion

This chapter has described the process of the Systematic Review and has summarised the two overarching themes from the meta-ethnography of participant experience: “Person-centred Care?” and “Intervention Design”. Chapter 7 will expand on this to present the BOTT analysis findings, before discussing how both these results fit within the wider literature base.

Chapter 7 Results: Burden of Treatment Theory Analysis

7.1 Introduction

7.1.1 Aim

This chapter presents the findings from the Burden of Treatment Theory (BOTT) analysis, the narrative summary on social context and self-management, before discussing all the results in the context of the wider literature.

7.1.2 Rationale

Chapter 6 presented the insights obtained from the meta-ethnography analysis of the systematic review. This chapter will build on this, discussing the methodology utilised for the BOTT analysis before discussing the remaining findings. It will then situate the findings within the wider literature base before briefly discussing the strengths and limitations of the review.

7.2 Methods

The search, appraisal and initial data extraction were described in Chapter 6.

7.2.1 Burden of Treatment Analysis

A summary of the impact of Burden of Treatment theory, and social context was derived in the initial data extraction process. Table 7.1 shows the conceptual framework based on previous work (Chikumbu et al., 2022) that was then applied to each paper.

Table 7-1 Table summarising key Burden of Treatment Theory Constructs

Capacity - Individual	
1: Mobilising capacity – Capacity of individuals and their relational networks to interact and utilize healthcare services	
1.1: Agency	Things people do to engage with health problems and with others: impact of physical/psychological/sensory aspects of disease and disability; material and cognitive resources at their disposal
1.2: Relationality	Social networks through which agency can be expressed and distributed: intensity, size, and complexity of relational networks (which may vary over time). Will include health professionals
1.3: Opportunity	Availability of services varies by time and area.
1.4: Control over service	What organisations do to determine the content, structure, and resources of services.
2: Expressing capacity – the qualities patients and their relational networks need to possess if they are to exploit healthcare opportunities.	
2.1: Social Skill	Skills necessary to engage and mobilise the cooperation of others, and to negotiate controls placed on resources to help with the tasks of care.
2.2: Functional Performance	Degree to which people possess the cognitive and material capacity to meet demands.
2.3: Structural resilience	How the patient’s network of support can be used to absorb, compensate, and even thrive when things change.
2.4: Social Capital	How the patient’s social network can be used for gaining information and resources that help with care.
Treatment Burden	
3: Mobilising and enacting delegated tasks – how patients sustain and modify their role (including self-management)	
3.1: Sense Making (coherence)	The way sick people and their social networks identify, understand, and explain the diverse tasks that make up work, internalize these and plan for their requirements
3.2: Building and maintaining relational networks (cognitive participation)	How patients and their networks enrol, engage, and maintain contacts in their support network.
3.3: Enacting delegated work (collective action)	How patients and their networks allocate and execute specific tasks, negotiate accountability for outcomes and organise and realise the mobilisation of resources
3.4: Reflexive monitoring	Collecting information regarding sign and symptoms and views of sig others, undertake its individual and collective appraisal and apply it to the reconfiguration of their work

Relevant data related to the above concepts were extracted. Finally, each paper was assessed by two independent researchers, to determine whether the intervention caused an increase, decrease or no difference to treatment burden. A similar assessment was made regarding enhancing or reducing capacity.

7.2.2 Social Context and Self-Management

Each of the papers were assessed to determine types of intervention based on the criteria used in the Cochrane review of multimorbidity interventions (Susan M. Smith et al., 2021). Any self-management components were identified using the PRISMS self-management taxonomy (Pearce et al., 2016). A narrative summary of the role of social context was carried out for each paper.

7.3 7.3 Results

BOTT (Carl R. May et al., 2014) was not explicitly used or discussed in any of the interventions' design. One of the interventions did explicitly seek to reduce, and attempt to measure, treatment burden (though no other aspects of BOTT) (Mann et al., 2019) and several explicitly sought to reduce patient work via deprescribing or changing how care was delivered.

However, there was no evidence any of the interventions had considered whether the intervention itself required extra work, or if the potential benefit to the patient justified that increased workload. The impact of social context and potential barriers to self-management were not explicitly considered.

7.3.1 Capacity

The underlying capacity of participants was not explicitly discussed; enhancing this was not an explicit aim of any intervention, though several sought to increase knowledge and confidence managing multimorbidity. This lack of consideration of participant capacity could be an important barrier to intervention efficacy. The lack of in-depth exploration of participant experience means themes related to capacity have often been extrapolated, which should be considered during interpretation of the findings.

Table 7.2 summarises how each intervention influenced capacity, including a summary whether overall the intervention appeared to enhance, diminish, or have no effect on capacity. The analysis identified the importance of “building” capacity (discussed below), and this is included in the summary where relevant.

Table 7-2 Table summarising how each identified intervention impacted on capacity, and whether overall the intervention enhanced or diminished this.

Paper	Summary of how intervention impacted participant Capacity	Overall Impact
Blixen et al (2015)	Paper explored experience and training of peer educators. Evidence for peer educators, and early participants, that intervention built a new supportive and informative social network that appeared to enhance structural resilience and social capital.	Likely enhanced and built capacity
Boeckxstaens et al (2020)	In theory should increase capacity by opportunity of new service and changes in controls to improve access for those requiring co-ordinated care. Only professionals interviewed so impact on participants unclear.	Neutral (not enough evidence to know if increased opportunity enhanced participant capacity)
Edlind et al (2018)	Highlighted importance of agency and relationality in engagement. Community Health Worker role also appeared to support expression of capacity by building social skills to negotiate and manage behaviour change tasks.	Likely enhanced capacity
Ford et al (2019)	Intervention applied universally; underlying capacity not considered. Some participants may need time to think through and decide on goals (Mann et al., 2018, Mann et al., 2019), others may struggle cognitively -this was not explored.	Neutral (potential that not everyone could access intervention)
Knowles et al (2015)	Intervention primarily about co-ordinating care, did not directly consider capacity (though an improvement in health conditions, particularly mental health would be expected to improve capacity indirectly by improving functional performance). Co-location of services reduced stigma so could have increased opportunity for some.	By increasing opportunity potentially enhanced capacity for some patients
Li et al (2019)	The aging worker role built both social capital and structural resilience, as well as improving relationality between family and practitioners. Screening and treating for hypertension and depression likely improved functional performance further enhancing capacity.	Enhanced Capacity
Mann et al (2018 and 2019)	Intervention introduced bi-annual reviews, with a nurse, followed by GP. Aimed to identify participant priorities and use shared decision making to developed management plan. Shared management plan may have enhanced capacity if it helped participants to express capacity	Potentially enhanced capacity
McCallum et al (2019)	Intervention targeted impact of SED on factors impacting both agency and relationality. Increased opportunity and influenced control of services by providing an enhanced service for participants. Self-help resources may have improved functional performance	Enhanced Capacity.
Middlemass et al (2017)	Did not consider capacity, the anxiety some patients felt recording results without understanding what they meant may have decreased their capacity	Neutral, may have diminished capacity for some
Sussman et al (2016)	Explored influence family and friends on engagement in the intervention. Highlighted importance of relationality. Intervention did not directly influence this, self-management resources with/without telephone support, may indirectly improve functional performance	Neutral – may have enhanced for participants who benefited from the self-help resources
Zechman et al (2019)	Capacity not targeted, focus on reducing medication. Highlighted importance of relationality in context of professional relationship	Neutral

7.3.1.1 Mobilising Capacity

The mobilising capacity construct summarises access to resources required to access and utilise healthcare services. Most interventions did not consider participant's agency in design or implementation. Despite this participant accounts suggested these were critical factors in their engagement.

> Several patients in the slight and no improvement groups mentioned being signposted, or even referred, to other agencies but they did not engage. Feeling it would not help, or other factors such as transport or finances, were cited as reasons:
>
> *"It's alright saying 'go and do these things' but if you've not got the money to go a. . .'cause like I can get eh the Glasgow thing, and you get for half price, but even half price I cannae afford that either because eh finances."* Patient 5, slight improvement, three months
>
> (Gray C M McCallum M, Hanlon P, O'Brien R, Mercer SW,, 2019)

One exception was Li et al's study in rural China which included a dedicated "Aging worker" role. This sought to improve participants' underlying resources and social support, enhancing both mobilisation and expression of capacity.

Several interventions provided self-management, educational resources, or opportunities for goal setting. While a degree of cognitive ability and confidence is required to be able to undertake these tasks, this was often not considered in planning.

> Some GPs commented that patients had not given prior thought to what they wished to address and that sometimes it was difficult to identify problems to include in the plan.
>
> *That's where I think perhaps them thinking in advance about their goal setting would help aid the conversation because often they say 'No, no there's nothing I want to discuss' and you eventually tease out one or two things from them."* [Interview BeddoesGP1]
>
> (Mann et al., 2019)

Improving relationality (social networks through which agency can be expressed and distributed, including medical professionals) was indirectly targeted in several interventions. Interventions that sought to build on, and improve, the practitioner relationship by providing longer flexible reviews were valued by practitioners and participants alike.

> ‘*This gives me that kind of overview where you think “well I’m the person that’s getting attended here, it’s not what this GP wants or thinks it’s what … my needs are”.’* (Lovell, Pt7, focus group)
>
> (Mann et al., 2018)

Sussman et al (2016) focused solely on family and friends (F/F), exploring their experience of the intervention, rather than those of the participants. This provided important insights into just how complex relationality, and trying to enhance it, is. Few F/F felt they had been a direct support despite participants identifying them as having done so. F/F find it hard to know what the “right” thing to do to help is, with concerns they could do more harm than good.

> As one daughter stated, *‘‘I don’t know I really feel this is something he has to do on his own. . .if his family is pushing him it would make him withdraw more.’’*
>
> (Sussman et al., 2016)

Supporting participants with LTCs is complex and difficult and attempts to help can be interpreted as criticism.

> Many F/F could recount moments when support was not easily provided or readily received. One wife noted how her efforts at encouragement were experienced by her husband as non-supportive. She stated,*‘‘. . . and he feels I’m always interrupting, but I try my best, um I try to just stay calm and be supportive as much as possible.*’’ A sister who also noted her sibling’s negative reactions toward her gestures of support stated, ‘‘*I need to try and stay even. I’ve learnt how to control my emotions a little more so I don’t react as much, but there are times when it’s harder I guess.’’*
>
> *(Sussman et al., 2016)*

Practical support like shopping or taking people out was much easier and better received than emotional support. Interestingly several family and friends found in the process of providing practical support, emotional support could be given indirectly which appeared more beneficial for the participant.

> While some F/F struggled with the provision of emotional support most found it easier and rewarding to provide practical support such as assistance with shopping, meal planning, medical visits, and recreational activities. In these instances, F/F appraised their assistance as ‘‘helpful’’ and ‘‘mutually beneficial.’’ When done alongside patients, these tasks could also serve as a form of connection, distraction, and pleasure.
>
> (Sussman et al., 2016)

Enhancing relationality is likely important in enhancing engagement and potentially improving intervention outcomes, but preferences vary, and individual situations are often complex. However, F/F views are rarely considered, and their experience is rarely evaluated; doing so could provide valuable information. Exploring the difference intentionally supporting F/F makes could inform the design of future interventions.

Several interventions made organisational changes to care delivery and therefore intervened directly in ‘opportunity’ and ‘control’ domains (Boeckxstaens et al., 2020, Ford et al., 2019, Knowles et al., 2015, Li et al., 2019, Mann et al., 2018, Mann et al., 2019, McCallum M et al., 2019, Middlemass et al., 2017, Zechmann et al., 2019). For example, provision of new targeted services altered availability and ‘opportunity’ (Mann et al., 2018, Mann et al., 2019, McCallum M et al., 2019); reconfiguring services by, for example co-locating mental health services within a GP practice directly influenced ‘control’ (Knowles et al., 2015). Such interventions resulted in improved communication between professionals, reduced stigma and increased time and resource to explore participants’ concerns in detail.

Yet, additional opportunity did not always equate directly with benefit. In one intervention, telemonitoring was introduced into participants’ homes to collect data on cardiac and respiratory parameters. However, participants were often not clear on the intervention’s purpose, which created anxiety.

> “I’m in a vacuum... I’m doing something, I’m sending it off to you, [but] there’s no feedback… You‘d be seeing something for your efforts whereas looking at nothing…I don’t think you should be placed in a vacuum for nine months and say blow into this every day.”
>
> (Middlemass et al., 2017)

7.3.1.2 Expressing Capacity

Expressing Capacity examines factors that influence patient ability to utilise the resource they have access to. Several interventions (Blixen et al., 2015, Edlind et al., 2018, Li et al., 2019) introduced flexible supportive roles (peer educators, community health workers, local village workers) that had a positive impact on both structural resilience (how social networks can absorb, compensate and even thrive when things change) and social capital (how social networks can be used for gaining information and resources that help with care).

> The family is an important support system for older patients. VDs [village doctors] and AWs [aging workers] felt that older patients' family support increased as a result of the COACH intervention, due partly to reduced depressive symptoms and partly to the education of their family members. As explained by an AW and a VD:
>
> *I ask adult children of older patients to visit their parents as frequently as possible. Older people need care and concern from their children more than anything. It's more effective than medicine. So we talk to the adult children. (AW1B)*
>
> *Due to [the older person's] depressive symptoms, family members find it hard to communicate with them. After our intervention, their mood elevates and the communication with family members is improved. The whole family atmosphere is much better. I feel very good seeing that. (VD2A)*
>
> (Li et al., 2019)

As well as the aging worker role enhancing social skills, structural resilience, and social capital, Li et al's study also likely improved functional capacity by diagnosing and managing depression.

7.3.1.3 Building Capacity

Several interventions increased participant's workloads, at least in the short term (increased visits, potential medication increases as screening revealed undiagnosed conditions, learning new information or skills) (Blixen et al., 2015, Li et al., 2019, McCallum M et al., 2019, Sussman et al., 2016). However, this increased work would be expected to enhance understanding of LTCs, reduce symptom burden and therefore build capacity in the long run and thus ultimately reduce treatment burden. Short-term increase in work may be necessary to build capacity in the long-term (Kasey R. Boehmer et al., 2016).

7.3.2 Treatment Burden

While several interventions sought to reduce participant work overall none of them discussed the added work of the intervention itself. As discussed, an increased amount of short-term work may be worthwhile if it leads to reduced workload in the future. However, whether participants currently had capacity for this extra work was not considered. In addition, there was some evidence of increased work (e.g., extra reviews, measuring readings) which did not improve current or future outcomes. Table 7.3 describes whether interventions increased, decreased, or had no impact on treatment burden.

Table 7-3 Table summarising impact of intervention on Treatment Burden and whether overall the intervention enhanced or diminished this.

Paper	Summary Intervention impact on Treatment Burden	Overall Impact
Blixen et al (2015)	Extra "work" attending training and/or education classes, improved participant's understanding of their illnesses, the work to manage it and how these interacted. Evidence development to enact new management plans increased confidence.	Reduced
Boeckxstaens et al (2020)	MDT management would be expected to improve care co-ordination. Practitioners were positive but patients not interviewed	Likely Reduced
Edlind et al (2018)	Increased work as it supported people to enact significant behaviour change in relation to one chronic disease. However, skills gained and expected improvement in symptom burden would likely increase capacity and reduce future work.	Increased, with potential long-term reduction
Ford et al (2019)	Allowing participants to develop and set goals likely supported coherence work. No resource in place for meeting goals once set – may have increased burden for some	Potentially increased
Knowles et al (2015)	Co-location valued by professionals but mixed experience for patients. Narrow remits of the trial did not meet some participant concerns potentially increasing coherence work	Neutral
Li et al (2019)	Positive screening with subsequent treatment did increase work but may have reduced symptom burden long-term. Received multiple visits, but these appear to have been valued (although practitioner's view). Co-ordinated team, particularly the aging workers, appears to have significantly supported families to support their elderly relative.	Reduced
Mann et al (2018 and 2019)	Several reviews conducted which were considered extra work for some especially if no issues identified in nurse review. Again, no extra resource if required to enact management plans created by participants. Not clear if management plans reduced overall work, pharmacist review with aim of deprescribing likely did.	Unclear
McCallum et al (2019)	Attending Care plus reviews involved some work but these reviews appear to have supported participants to carry out and reduce the work required in the long-term.	Reduced
Middlemass et al (2017)	Increased work collecting data from the devices. In theory no extra work as clinician reviewed data but as no feedback often created anxiety.	Increased
Sussman et al (2016)	Provision of a CBT self-help resource, potentially with telephone support, likely supported coherence work. Family/friend resource sheet does not appear to have been used or helpful.	Increased
Zechman et al (2019)	Deprescribing intervention, using shared decision making. Should reduce treatment burden overall.	Reduced

7.3.2.1 Coherence (sense-making) Work

Several interventions involved giving information to enhance knowledge and understanding, or support decision making regarding managing illnesses. In some there was evidence of participants having limited understanding of illnesses prior to the intervention, particularly how these and their treatments may interact with one another. A further issue contributing to coherence work was the confusion caused when given different messages by different professionals. Where this was explored (either in facilitated classes, or during flexible reviews) there was evidence of increased understanding of their conditions. This in turn is likely to lead to reduced coherence work, and more confidence in making treatment decisions.

> *'I felt more confidence, maybe not more confidence, but more competent. The things that I was thinking about are not way out of left field, other people are having the same thoughts or same concerns. So I felt more in step with the program, with the manual and what we were expected to do and what others were doing'.* Respondent 3
>
> (Blixen et al., 2015)

7.3.2.2 Cognitive Participation (building and maintaining relational networks)

Cognitive participation is the relational work involved with maintaining social support networks, including with healthcare professionals. This work is increased in multimorbidity as fragmented care is recognised as a particular issue (Skou et al., 2022). Several interventions focused on care co-ordination: between primary and secondary care, or between physical and mental health services (Boeckxstaens et al., 2020, Knowles et al., 2015). This improved professional communication and gave practitioners a deeper understanding of patient's wider needs, and the roles of the wider team. This would be expected to reduce cognitive participation as patients are not taking on this co-ordinating role for themselves.

> *"I think the greatest benefit is that, because we're all sitting down together at the same table, we can talk about how these things interact and intersect. So, for example, pharmacy can talk about adverse drug interactions that may be contributing to mental illness or making it worse. And then together with social work at the table*

> *we can all comment on how we think this is impacting activities of daily living."* (GIM 09)
>
> (Boeckxstaens et al., 2020)

Knowles et al (2015) who trialled co-location of physical and mental health services), found it was increased communication between professionals that was appreciated (in some cases improving care co-ordination). Both patients and practitioners, however, often preferred consulting work to be separate.

> PWP04: *"I think, you know, as I say, my area is obviously mental health, and her area was more physical health… So there was no real, you know, crossover*"
>
> (Knowles et al., 2015)

7.3.2.3 Collective Action (enacting delegated work)

Collective action involves negotiating, allocating and enacting the work of LTCs. Interventions that sought to co-ordinate care amongst professionals, appeared to support this work e.g., where MDT meetings or reviews agreed joint plans (Boeckxstaens et al., 2020, Knowles et al., 2015, Li et al., 2019). However, for those that sought to identify participant goals and priorities it is important to note that no extra resource was provided to support participants to develop or enact strategies to meet these priorities (Ford et al., 2019, Mann et al., 2018, Mann et al., 2019). It may be that while these interventions reduced the work of allocating tasks, with no extra resource to carry those tasks out they may not have ultimately reduced treatment burden.

Some of the interventions did support collective action by providing continuity with one doctor or using a different role which was valuable (Edlind et al., 2018, McCallum M et al., 2019). Like some of the constructs already discussed, increasing work to enact agreed plans (e.g., health behaviour change, improved medication adherence) may confer a benefit by reducing work, or symptom burden, in the long-term.

7.3.2.4 Reflexive monitoring (appraisal work)

Reflexive monitoring is the work of appraising signs and symptoms (individually, or collectively by incorporating the views of significant others) and reconfiguring work as required. Several interventions (Blixen et al., 2015, Edlind et al., 2018, Li et al., 2019) that introduced lay educator roles (peer educators, village workers, community health workers) used these roles to support reflexive monitoring in a way that was often empowering.

> *"It was a wonderful experience for me. I enjoyed working with the other PEs [peer educators] and hearing their side and identifying my side with their side. You know with some of the things that they talk about that I had to learn about myself and to get with myself with that way of life when I found out about my diabetes and my serious mental illness. It was a wonderful experience and I enjoyed it and I would do it again'.* Respondent 6
>
> (Blixen et al., 2015)

In addition, those that included flexible reviews (Mann et al., 2018, Mann et al., 2019, McCallum M et al., 2019) allowed participants to drive the agenda, reflect on what improved their symptoms and make decisions based on their priorities in collaboration with their practitioner.

> Several participants who had not been taking their medication prior to CARE Plus started to do so as the consultations made them focus more on their health. For one participant understanding the difference these changes made in reducing the risk of a stroke (a major worry as her mother had died of one) was a markedly positive achievement:
>
> *"she actually phoned me the next day and said to me that, you know em, going through everything my weight and stuff like that blood pressure and things, em that I had actually reduced my chances of having a stroke to 11%, which I says to her 'oh you're joking'. I says to her 'I knew it would reduce it considerably but I didnae think it would be as good as that'. She says 'so that's fantastic'. So I put the phone down and I thought 'oh how good is that!" Participant 3 (female, 54)*
>
> (Gray C M McCallum M, Hanlon P, O'Brien R, Mercer SW,, 2019)

Critically, reflexive monitoring requires understanding the work's purpose: Middlemass et al (2017) asked participants to record multiple readings on telemonitoring devices which went to clinicians, who only contacted them if concerned. This significant work, the results of which were not understood and could not be directly acted on by the participant, caused confusion and frustration.

> “You can do it a few days on the run and you’re not getting no [any] response and you think, it feels like a non-entity really…, you think what’s the point?..the questions that are asked are easy and basic, …it’s a straight-forward yes or no answers but you’re not getting no [any] response.”
>
> (Middlemass et al., 2017)

This suggests some people with multimorbidity may wish a more active role; the process of reflexive monitoring while being work may also be a chance to assert agency and control.

7.3.3 Social Context

Social context of participants was not reported in any detail. There was some information in studies that had targeted specific population areas (low-income urban neighbourhood in USA (Edlind et al., 2018), people living in areas with high SED in the West of Scotland (McCallum M et al., 2019), villagers in rural China (Li et al., 2019)). However, even here, information regarding individual social circumstances was lacking, with no evidence that participants’ wider social contexts beyond being in the target group were considered.

Participants perceived the role of family and friends as important, though only one paper directly spoke to family and friends (Sussman et al., 2016) presenting a mixed and complex picture. One intervention targeting elderly villages in rural China (Li et al., 2019), suggested there may be increased value targeting the family unit, rather than the individual (practitioner view, no participants interviews).

> The family is an important support system for older patients. VDs [village doctors] and AWs[aging workers] felt that older patients’ family support increased as a result of the COACH intervention, due partly to reduced depressive symptoms and partly to the education of their family members.
>
> (Li et al., 2019)

The setting in rural China (others were all in Western nations), where many live in multigenerational family units may influence this view. However, supporting participant social networks rather than the individual is rarely done and could be an untapped resource that could be explored.

7.3.4 Self-Management

Only some of the multimorbidity interventions were patient facing and provided self-management support. This is summarised in Table 7.4. Providing information was the most common self-management support described.

Table 7-4 Table summarising the self-management components used in each intervention using the PRISMS taxonomy (Pearce et al., 2016)

Paper	Type of Intervention	Components of PRISMS taxonomy where relevant
Blixen et al (2015)	Patient facing provision of education and self - management support	A1. Information about condition and /or its management A2. Information about available resources A8. Provision of easy access to advice or support when needed A13. Social support A14. Lifestyle advice and support
Boeckxstaens et al (2020)	Organisational – co-ordinating primary and secondary care practitioners	N/A
Edlind et al (2018)	Patient facing – provision Community Health Workers to support behaviour change	A5. Monitoring of condition with feedback A6. Practical support with adherence (medication or behavioural) A14. Lifestyle advice and support
Ford et al (2019)	Organisational provision enhanced reviews with goal setting	N/A
Knowles et al (2015)	Organisational co-location of mental health services withing general practice	N/A
Li et al (2019)	Organisational – co-ordinating psychiatrists with village doctors and aging workers	N/A
Mann et al (2018 and 2019)	Organisational collaborative reviews to re-focus patient treatment priorities	N/EA
McCallum et al (2019)	Primarily organisational whole system intervention providing enhanced reviews. CBT self-help management pack given as part of intervention	A2. Information about available resources A12. Training/ rehearsal for psychological strategies
Middlemass et al (2017)	Organisational – provision specialist equipment with clinical remote monitoring	N/A
Sussman et al (2016)	Self-management resource issued to participants with and without telephone support	A1. Information about condition and /or its management A2. Information about available resources Intervention arm has A4, regular clinical review
Zechman et al (2019)	Organisational deprescribing intervention	N/A

7.4 Discussion

This qualitative systematic review used both meta-ethnography and framework analysis to explore participant experience of, and consideration of BOTT constructs, in primary care based multimorbidity interventions. The paucity of literature represents a significant gap. In addition, much of the work done has focused on practitioner experience, or participant experience of implementation rather than experience of the wider intervention. Furthermore, only three studies explored in any detail the experience of those who had not completed, or benefited from, the intervention – a critical omission.

The meta-ethnography findings show person-centred care definition is not clear in this context from a patient perspective. Practitioners appear to wish to practice in a person-centred way and structures within an intervention can shift care in that direction. However, current organisational structures and lack of resource often result in reversion to usual care. Practitioners' sense of duty to manage chronic disease well and, in some cases, professional identity, further drive this reversion to usual care.

Furthermore, interventions require a clear structure that is evidence-based and has practitioner buy-in. However, interventions must also be flexible to fit around participant's context. Interventions that integrate flexibility, while permitting fidelity to the evidence base may be more effective by enhancing engagement, while focusing on their stated outcomes.

None of the interventions explicitly considered treatment burden, capacity, or social context in any detail in the design or implementation of the intervention. Given their importance in the experience of multimorbidity and ability to self-manage this appears to be another critical omission (Barnett et al., 2012, Carl R. May et al., 2014, Shippee et al., 2012). However, many of the interventions appeared indirectly to reduce treatment burden and enhance capacity. Specifically targeting BOTT constructs, and considering social context, would be valuable in future intervention design. Finally, although the research question looked to explore different self-management strategies used in these interventions there was limited evidence to be able to draw conclusions.

7.4.1 Comparison to other literature

7.4.1.1 Person Centred Care (PCC)

While recognised as important, this review revealed considerable ambiguity over what constitutes PCC. This is reflected in the wider literature where there is *conceptual ambiguity* (A E MacFarlane, McCallum M, Stewart M, 2023) due to multiple definitions used in multiple contexts (Ahmad N, 2014, Mead and Bower, 2000, Stewart, 2001, The Health Foundation, 2016). Despite this, a recent review examining conceptualisation of PCC definitions (Sturgiss et al., 2022) demonstrated common themes that underpinned them all: sharing power; sharing responsibility; therapeutic relationship/bond/alliance; patient as a person; biopsychosocial; provider as a person; co-ordinated care; access; and continuity of care (Sturgiss et al., 2022).

It also demonstrated *conceptual partiality* (A E MacFarlane, McCallum M, Stewart M, 2023); with little patient involvement in their creation (Sturgiss et al., 2022). Similar to this review only 15% of the papers in the review by Sturgiss et al. (2022) included any patient perspective (Sturgiss et al., 2022). This "*lack of the perspective of the patient…. appears to be in direct conflict with the stated intentions of those interested in increasing centredness and leaves us wondering, whom is at the centre*?" (Sturgiss et al., 2022). In addition, different professional groups define PCC in different ways, prioritising different components depending on their professional standpoint (Gillespie et al., 2004).

This review suggests simply eliciting patient concerns, or goals, with no extra resource is unlikely to be successful. A similar picture is seen in the wider literature where many of the recommendations regarding PCC involve suggestions for clinicians and patients to adopt; the assumption being these can be readily adopted into the existing system with no extra resource other than training (Coulter, 2011, De Silva, 2012, Finnis A, 2016, Innes, 2006, Royal College of General Practitioners, 2021). However, evaluation of PCC implementation has demonstrated (as did this review) that the way the health system is currently configured restricts clinician ability to practice in a more PCC way (De Silva, 2012, Innes, 2006, McCallum and MacDonald, 2021, Lucy Moore et al., 2017).

7.4.1.2 Intervention design and the importance of context

Participant context is infrequently considered during intervention design (Glasziou et al., 2008). This is despite strong evidence that in complex interventions interaction with context is critical for design and evaluation (Skivington et al., 2021, Wells et al., 2012). While previous intervention design guidelines suggest broadly linear models (Craig et al., 2008, de Zoysa et al., 1998) the recent Medical Research Council (MRC) framework for designing and evaluating complex interventions (Skivington et al., 2021) recommends four phases (develop/identify intervention, feasibility, implementation, evaluation). These phases may overlap, their order decided by circumstances and the research question (Skivington et al., 2021).

Previously intervention efficacy focused on standardised randomised controlled trials which can provide strong evidence for narrow specific questions. However, current research questions and priorities are broad and complex. Multimorbidity research is an excellent example where answers to key questions may not be easily answered by narrow RCTs (Academy of Medical Sciences, 2019). Therefore, for complex interventions, the focus has shifted beyond efficacy to understanding in depth how the interventions components interact with each other, and their context (Hawe et al., 2004, Skivington et al., 2021, Wells et al., 2012). Current guidance recognises the importance of defining and evaluating an identified “mechanism of change” (Wight et al., 2016).

Flexibility is also required; indeed complex interventions are often complex because they offer flexibility (Skivington et al., 2021). Complex interventions should interact and adapt to their contexts, any intervention unable to adapt may lose its effectiveness as social conditions change (Moore et al., 2021). Flexibility is valuable not just in design and implementation but in monitoring. Ongoing monitoring of interventions is valuable to identify spontaneous adaptations and ensure these do not negate underlying intervention principles (Moore et al., 2021). Ongoing adaptation of interventions, particularly in different contexts, is not necessarily wrong (and may be healthy) but new adaptations need to be recognised and transparently reported (Moore et al., 2021, Wells et al., 2012).

This review showed a dearth of qualitative evaluation of current multimorbidity interventions, with very few examining the experience of those who had not benefited. This is at odds with current recommendations which stress the importance of stakeholder consultation at every stage (Hawe et al., 2004, Skivington et al., 2021). Qualitative work is particularly valuable, providing rich detail of how, for whom and why an intervention works (Bunce et al., 2014, Hawe et al., 2004, O'Cathain et al., 2013, Skivington et al., 2021).

7.4.1.3 Treatment burden and Capacity in the context of multimorbidity interventions

Treatment burden is increased for patients with multimorbidity and has a significant impact on quality of life (Rosbach and Andersen, 2017, Adem Sav et al., 2013, Shippee et al., 2012). There are a few current measures for treatment burden (Polly Duncan et al., 2020, Eton et al., 2017, Tran et al., 2012) and measuring and accounting for treatment burden in routine care, and intervention design, is likely critical to improve outcomes for patients with multimorbidity. Of particular importance, none of the articles considered the increased work of the intervention itself. This is in keeping with a review of interventions based on the Chronic Care Model which found that none addressed patient workload, and few reduced it without adding other work (K. R. Boehmer et al., 2018). This means interventions will favour those with higher pre-existing capacity, while potentially prejudicing those who could have benefited with some support (and arguably may need the intervention most).

However, introducing work may have long-term benefits if participants develop new skills; improved understanding may enhance participant autonomy in terms of decision making. This is reflected in the BREWS model (discussed in chapter 3) where *“realisation of work”* is one of the components enhancing capacity (Kasey R. Boehmer et al., 2016). However, it is likely, even with potential long-term benefits, a proportion of patients may require increased resource and support to increase any element of work. At present there are no capacity measures which means that any impact of current interventions on capacity must be inferred.

7.5 Strengths and Limitations

This review utilised a wide-ranging search strategy, based on a previously published search strategy, to ensure identification of as many relevant papers as possible (Susan M. Smith et al., 2016). The use of the interpretative meta-ethnography methodology produced results rooted in the original data which also generated wider over-arching themes that can directly inform further work. The framework analysis was underpinned by BOTT, which is well established and has been used in previous reviews (K. Gallacher et al., 2011, Katie Gallacher et al., 2013b).

One limitation of this review is the paucity of the literature identified. This is partly because although the research in multimorbidity is increasing there are still small numbers of high-quality randomised interventions in this area. Evaluation by a randomised trial was an inclusion criterion to ensure a focus on high quality interventions recognising the growing numbers of interventions, and service changes, of varying quality in the context of multimorbidity. Screening identified numerous service interventions targeting multimorbidity, which were of varying quality, and where evaluation did not involve randomisation. Exclusion allowed a focus on interventions evaluated to a high standard, but there may have been valuable findings in the work done on service level interventions.

There were also two papers that explored the experience of an intervention where most, but not all, of the participants had multimorbidity. The results for people with multimorbidity were not reported separately meaning these studies could not be included (Bleijenberg et al., 2013, M. Fortin et al., 2019). Finally, there were several studies that targeted specified co-morbidities, but were primarily focused on improving outcomes in just one of these morbidities and therefore these were excluded. This highlights some of the difficulties with searching the literature for multimorbidity.

In addition, like every meta-ethnography, the results are influenced by the background and experience of the meta-ethnographer. While not necessarily a limitation, it should be recognised that a similar methodology used by someone different may have come to similar, but slightly different conclusions, or may have emphasised different aspects of the findings.

7.6 Conclusion

This chapter demonstrates that the findings from this review broadly reflect the wider literature underlining the importance of participant involvement in future interventions, especially ones aiming to be more person-centred. The findings also highlight the recognised need to ask participants, not just practitioners, about what person-centred care means to them. Future interventions should ensure adequate evaluation, involving participants and practitioners, including a rigorous qualitative element which often produces important insights. In addition, the importance of understanding experience of those who do not engage, or benefit, is critical. The experience of wider family and friends may also provide valuable insights that could enable refinement of interventions. Finally, interventions in this context may particularly benefit from a clear evidence-based structure that also includes flexibility.

Chapter 8 Results: Quantitative Data Analysis

8.1 Introduction

8.1.1 Aim

This chapter presents the results from the quantitative work package and then the implications of the findings in the context of the wider literature as well as the strength and limitations of the work.

8.1.2 Rationale

The influence of single capacity factors on health outcomes, and healthcare utilisation, in the context of LTCs has been extensively explored (Fan et al., 2021, Koetsenruijter et al., 2016, Macintyre et al., 1998, Reeves et al., 2014, I. Vassilev et al., 2014, Ivaylo Vassilev et al., 2016). Factors such as social networks (Koetsenruijter et al., 2016, Reeves et al., 2014, I. Vassilev et al., 2014, Ivaylo Vassilev et al., 2016), tenancy (Macintyre et al., 1998), health literacy (Fan et al., 2021) and transport access (Macintyre et al., 1998) are all important in a wide range of health outcomes. However, how a range of these factors may influence outcomes, and which ones are particularly important remains unclear.

Burden of Treatment Theory (BOTT) recognises the importance of how multiple factors interact to influence both capacity and treatment burden on outcomes in the context of LTCs (Carl R. May et al., 2014, Shippee et al., 2012). This is particularly important in multimorbidity which both increases treatment burden and can further reduce capacity (Carl R. May et al., 2014, A. Sav et al., 2016, Shippee et al., 2012). Chapter 3 reviewed how BOTT primarily looks at the influence of capacity and treatment burden at the level of the individual. However, community factors are recognised to impact individual capacity (Carl R. May et al., 2014, Shippee et al., 2012), and in other contexts have been important separate to the existing BOTT constructs (Chikumbu et al., 2022, van Pinxteren et al., 2023a).

To my knowledge, no work has looked at how a range of capacity factors, rather than one single factor, influence the risk of mortality or healthcare utilisation.

Chapter 7 demonstrated that, despite a recognition of the importance of these factors in the context of multimorbidity, in current multimorbidity interventions the concepts of capacity, and treatment burden, are rarely explicitly considered. Understanding the extent to which these factors influence “hard” outcomes such as mortality and hospital admissions, and in particular which factors have the most influence on them, is crucial to understand potential cost-benefit gains, and inform future service, and intervention, design in this area.

8.1.3 Research Question

What is the impact, if any, of capacity (individual or community) and treatment burden on the risk of mortality and self-reported hospital admissions?

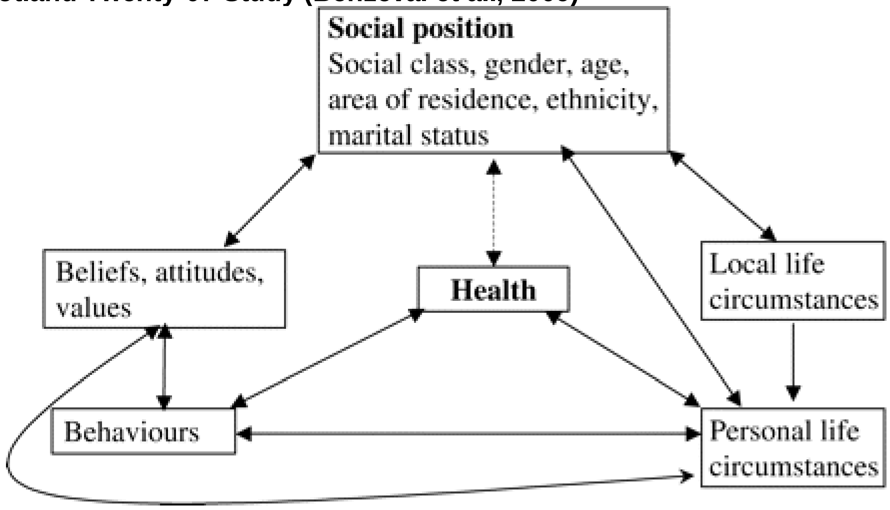
8.2 Methods

8.2.1 Study Design and Participants:

8.2.1.1 West of Scotland 20-07 Cohort

The West of Scotland Twenty-07 (WoS 20-07) cohort was designed to *“investigate longitudinally, the social process producing or maintaining inequalities* (Benzeval et al., 2009). It followed up three separate age-based cohorts from 1987/88 to 2007/08; baseline data collection was followed by four waves of data collection over 20 years. It collected information on four broad categories: personal life circumstances, local life circumstances, beliefs/attitudes/values, and behaviours. It set out to understand how physical and social environment interact over time with health and six social positions (class/gender/age/area of residence/family structure and ethnicity): summarised in figure 8.1.

Figure 8-1 Model underlying Twenty-07 Study at conception, taken from Cohort Profile: West of Scotland Twenty-07 Study (Benzeval et al., 2009)

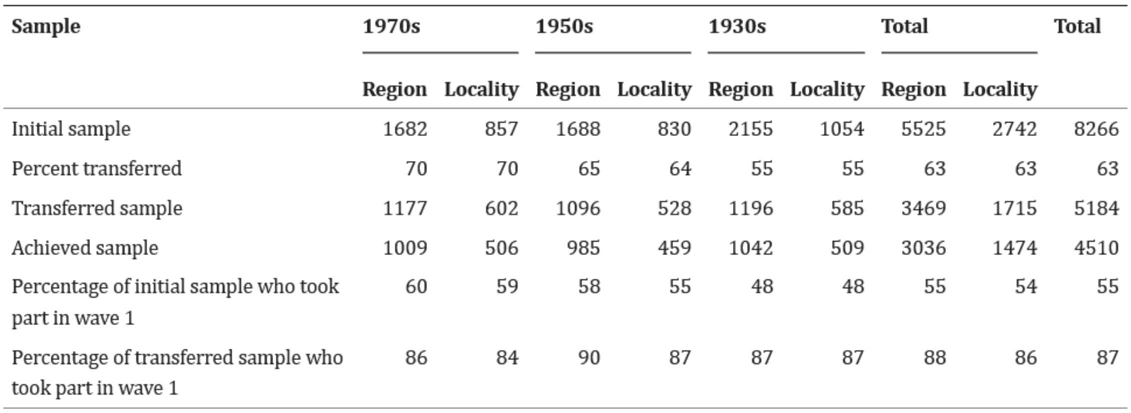


The cohort was sampled from across the West of Scotland using two specific sampling strategies, creating two samples. A regional sample was recruited aiming to be representative of the wider population (Benzeval et al., 2009). The researchers stratified local government districts by unemployment and socioeconomic deprivation (based on the 1981 census), selecting 52 postcodes across the region. In addition, a locality sample was created which aimed to allow a closer study of the relationship between environment and health. Ten postcodes in two areas of the city of Glasgow were selected to allow direct comparison (Benzeval et al., 2009).

Once the target population was identified, employees from the council approached potential participants requesting permission for details to be passed to the unit undertaking the study. Those who agreed were then approached by the study team, and, if willing, consented to participate in the study. Table 8.1 summarises the numbers of people at each stage; overall 55% of those approached agreed to participate in the final study. Comparison with data from the 1991 census demonstrated no significant difference in social class, car ownership, gender and housing tenancy between the cohort and general population apart from the youngest cohort which showed a slightly higher proportion of parental car ownership at baseline (Benzeval et al., 2009, Der, 1998).

Baseline data was collected in 1987/88 with further data collected across four waves in 1990/92, 1995/98, 2000/04 and 2007/08. In addition, several postal surveys were carried out more regularly with the younger cohort, and 12 nested studies (including qualitative work) were carried out throughout the cohort. This study only looked at the sequential longitudinal data collected at each wave, which were collected from both samples.

Table 8-1 from published cohort profile of the West of Scotland Twenty-07 cohort (Benzeval et al., 2009) demonstrating numbers initially approached, transferred and who agreed to participate by cohort.



Sample	1970s		1950s		1930s		Total		Total
	Region	Locality	Region	Locality	Region	Locality	Region	Locality	
Initial sample	1682	857	1688	830	2155	1054	5525	2742	8266
Percent transferred	70	70	65	64	55	55	63	63	63
Transferred sample	1177	602	1096	528	1196	585	3469	1715	5184
Achieved sample	1009	506	985	459	1042	509	3036	1474	4510
Percentage of initial sample who took part in wave 1	60	59	58	55	48	48	55	54	55
Percentage of transferred sample who took part in wave 1	86	84	90	87	87	87	88	86	87

8.2.1.2 Missingness

Missing data, and how to deal with it, is a common issue in real world research (Harrosin E, 2021), particularly in cohorts where attrition, and loss to follow up is inevitable. Identifying the pattern and likely mechanism(s) of missingness within the dataset is key. There are three main types of missingness assumptions in the literature (Harrosin E, 2021). Data can be missing completely at random (MCAR) with no pattern to the data missing for a particular variable. If missing data is removed it will not bias the analyses, although there will be some loss of statistical power. The MCAR mechanism is unlikely in real world situations, therefore most analyses require more sophisticated approaches to missing data.

Missing data can also be considered missing at random (MAR); there are systematic reasons for the missing data, and this is captured by other measured variables. For example, missing data is more likely to include people from a lower socio-economic group, or a particular gender. As discussed, the loss to follow up group in the WoS20-07 data were more likely to come from areas of higher SED, and less likely to be multimorbid. Simply removing all missing data would introduce a clear, and unintended, bias into any analysis.

Finally, data can be missing not at random (MNAR), where the missingness varies by reasons the researcher does not know about (Harrison E, 2021, Stef van Buuren, 2018). This can be very difficult to adjust for, cannot be empirically tested and results must be interpreted with this issue in mind. Recognising the type of missingness is important because this will in turn determine how to manage it (Harrison E, 2021, Stef van Buuren, 2018).

There were several specific issues for missing data in the WoS 20-07 cohort. Common to most cohorts there was attrition across the five waves of data collection, with certain groups less likely to be followed up as previously discussed. The follow up numbers at each wave are shown in table 8.2.

Table 8-2 Table summarising numbers, and percentages compared to baseline, of people participating (or not participating with reasons why) at each wave of the West of Scotland Twenty-07

Interview outcome at each wave	Wave 2 (1990/92)		Wave 3 (1995/97)		Wave 4 (2000/04)		Wave 5 (2007/08)	
	Number	% Baseline	Number	% Baseline	Number	% Baseline	Number	% Baseline
Refusal	221	4.9	478	10.6	374	8.3	346	7.6
Uncontactable	306	6.8	287	6.4	587	13.0	400	8.9
Not issued*	90	2	580	12.9	517	11.5	390	8.6
Dead	73	1.6	193	4.3	371	8.2	680	15.1
Respondent	3820	84.7	2972	65.9	2661	59.0	2604	57.7
Response rate (% living baseline sample)		86.1		68.8		64.3		68.0

***In waves 2 and 3 the decision was made not to ask participants who had refused in a previous wave, moved from the area, or withdrawn from the study. From wave four there was a change in policy and only those who had specifically withdrawn were not contacted**

The higher uptake in the final wave was due to a concerted effort to contact participants and encourage follow up (Benzeval et al., 2009).

In addition to missing from a particular wave, not all questions were answered by all participants so there was an element of within wave missingness (which was particularly common in questions that may be a bit more sensitive, e.g., income).

A further issue influencing missingness was the underlying structure of three age-based cohorts, where, particularly in the earlier waves, different cohorts were asked different questions. There were several important variables only asked of the oldest cohort in wave one, and the oldest and middle-aged cohort in wave two. The analysis was conducted on a subset of the cohort experiencing multimorbidity, meaning smaller numbers for the younger and middle-aged cohorts were in the earlier waves, so the impact of the missing questions was reduced, but remains a weakness in this analysis.

The cohorts also comprised of locality and regional samples, for most waves this made little difference as the same questions were asked. However, in the third wave the locality was sent a postal questionnaire to complete (with fewer questions in it), while the regional completed it in person (MRC Social and Public Health Sciences Unit). There was a much lower response rate from the postal group (60.4% compared to 74.1% from the face-to-face group (Benzeval et al., 2009)), and as they were asked less questions several variables were missing in larger numbers in wave 3.

Finally, the same set of questions were not asked at every wave, which meant some variables were only available at certain waves. Where possible, only variables available at every wave were included. Where a variable was felt to be of particular significance, and was only available at certain waves, its inclusion was discussed with the project supervisors to determine its relative importance as a capacity factor. It would be included if felt to be of particular importance (examples include health locus of control, and mastery questions).

To understand the pattern of missingness across the dataset tables were constructed for each potential variable identifying whether it (or an appropriate proxy) was measured at each wave, and for each cohort (and subset of cohort where relevant). Patterns of missingness between the selected variables were also explored (Appendix 14). These findings were then discussed with the project statistical supervisor and a consensus regarding the type of missingness for each variable was reached, which determined how it was managed in the final analysis.

It was clear that data was not MCAR, so multivariable imputation by chained equations (MICE) was used to manage the missing data under a MAR assumption (Janssen et al., 2010). Twenty imputations were used for all the models except the final fully adjusted mobilising capacity model which due to technical issues was run with 10 imputations. For those variables where the data was missing due to questions not being asked to specific subsets this is made clear in the presentation of results so that results can be interpreted within this context.

8.2.2 Study Variables

Tables 7.3 – 7.6 summarises, for each of the variables within the four constructs, it was measured, and whether there was any wave, cohort, or subset of cohort missingness.

Table 8-3 Table summarising Mobilising Capacity Variables

Variable	How Measured	Responses	Missing
Income	Participant asked to estimate household income, result then equivalised and adjusted to 1987 inflation to allow comparison across waves	Numerical	Asked across all waves and cohorts
Car access	Do you, or your household own a car or van?	Yes/no response	Asked across all waves and cohorts
Housing Tenancy	Participant asked to identify housing tenancy type	"Owner", "Social Housing", "private rental", "other tenure"	Asked across all waves and cohorts
Employment status	Participants requested to self-identify employment status	Full time education, employed/self-employed, carer or housewife, retired, unemployed, disabled.	Asked across all waves and cohorts
Life event – death family member	Combination value created for people who replied affirmatively to death of spouse, child, or close member of family in the previous two years	Yes/No	Questions asked differently across the waves. Cohort two at baseline were asked separate questions about "life events" in general, which created a score with no information on individual events. The youngest cohort was asked slightly different questions in waves 1-2, and there was no information on employment changes for this cohort. Wave three locality sample not directly asked about employment changes.
Life event -death friend	Death of a close friend in the last two years	Yes/No	
Life event – divorce	Divorce in the last two years	Yes/No	
Life events -unemployment	Been made unemployed in the last two years	Yes/No	
Life events – job change	Significant change in job status in the last two years	Yes/No	
Number family contacts/month	Wave 1-3 recorded number of times were in contact with different family members in last 4 weeks, waves 4 and 5 only record if	Yes/No	Asked across all waves and cohorts but different questions across the waves.

	family member were seen in last four weeks. Binary variable therefore used in analysis to allow comparison across waves		
Number friend contacts/month	Wave 1-3 recorded number of times were in contact with friends in last 4 weeks, waves 4 and 5 only record if family member were seen in last four weeks. Binary variable used in analysis to allow comparison across waves	Yes/No	Asked across all waves and cohorts but different questions across the waves.
Share feelings	Have you someone you can share your feelings with?	“All feelings”, “some”, “few”	W1 only asked oldest cohort, W2 only asked oldest and middle aged, W3 only asked regional sample.
Someone to confide in	Have you someone you can confide in?	“Very Frequently”, “quite often”, “Occasionally”, “Never”	W1 only asked oldest cohort, W2 only asked oldest and middle aged, W3 only asked regional sample.
Someone to offer practical Support	About how many people could you ask for practical help?	Numerical	Not asked W1, only oldest and middle-aged cohort W2, W3 only asked regional sample.
Loneliness	Do you ever feel lonely?	Never, seldom, occasionally, quite often, most of the time	W1 only asked oldest cohort, W2 only asked middle aged and oldest cohorts.
Carer	Are you a carer?	Yes/No	W1 only asked oldest cohort, W3 only asked regional sample

Social networks are recognised to be an important capacity factor in the context of chronic illness, and larger networks, even if the relationships within them are less close, appear to be particularly important (Koetsenruijter et al., 2016, Reeves et al., 2014, Ivaylo Vassilev et al., 2016). Therefore, variables within the model which could measure both number of contacts (as there may be a positive benefit where illness work can be shared with more people (Reeves et al., 2014)) as well as quality of relationships were selected. Unfortunately, while exploring the variables it emerged there was less information on number of contacts for waves 4 and 5 limiting how the influence of size of social network could be explored, which is a weakness of this analysis.

Table 8-4 Table summarising Expressing Capacity Variables

Variable	How Measured	Responses	Missing
Self esteem	Measured using Rosenberg's Self-Esteem Score: numerical score ranging from 10(low) to 40 (high)(Rosenburg, 1965)	Numerical score	Only asked in waves 2, 3 and 4 (only regional sample in wave 3).
Self-reported Health	Over the last 12 months would you say your health on the whole has been……	Good, Fairly good, Not good	Asked across all waves and cohorts
Health compared to Others your age	Would you say that for someone your own age your health in general is…	Excellent, Good, Fair, Poor	W1 only asked oldest cohort, W2 only asked oldest and middle aged, W3 only asked regional sample.
Health Locus of control	Set of statements: • I have the power to make myself well • I have no control over being ill • Regular doctor visits reduce health • Accidental happening influence health • Only doctors can maintain health • I am responsible for my health • Others are responsible for my health • It's my fault when things go wrong with my health • When I am ill, I let nature run its course • When I'm health it's because I am lucky • Wellbeing depends on taking care of yourself • Illness means you have not cared for yourself • Care from others helps me to get well • Illness is luck • Looking after myself keeps me healthy • Doctor's orders keep me healthy	Respondents could agree strongly, agree quite a bit, agree a little, disagree a little, disagree quite a bit, disagree strongly	All cohorts asked in W2 only.

Mastery	Set of statements: • I have little control over what happens to me • There is no way I can solve some of the problems I have • There is little I can do to change many of the important things in my life • Sometimes I feel helpless dealing with the problems in life • Sometimes I feel I am pushed around in life • What happens in the future depends mostly on me • I can do just about anything I set my mind to	Strongly agree, agree, disagree, strongly disagree	All cohorts asked in wave 4 only.
Disability	Are you registered as disabled?	Yes/No	Not asked wave 1, otherwise asked all cohorts each wave
Life limiting LTC	All participants were asked if their LTCs had a limit on their life	Not limited by LTC, limited by LTC	Asked across all cohorts and waves
Anxiety	Hospital Anxiety and Depression questionnaire (HADS), scores categorised by clinical cut-offs	No, mild, moderate, or severe anxiety	Asked across all cohorts and waves
Depression	HADS questionnaire scores categorised by clinical cut-offs	No, mild, moderate, or severe depression	Asked across all cohorts and waves
Educational attainment by age 35	Max educational attainment by age 35 (oldest age of youngest cohort at final wave)	Apprenticeship, Standard Grade, Higher, HND, degree.	One off variable summarising maximum educational achievement by the age of 35 (oldest age of the youngest group when the cohort finished). This allowed measure of educational attainment that could be standardised across the three cohorts.
Alice Heim 4 Test (AH4)	Standardised assessment, questions answered within a specific time that measures verbal and non-verbal ability	Numerical	Measured oldest cohort W1, and all three cohorts W4 and W5. As would be

			expected very high correlation between the three scores.
Number of community Groups	Number of community groups involved in	Numerical	W1 only asked oldest cohort, W2 only asked oldest and middle aged, W3 only asked regional sample.

Self-esteem, and the health locus of control and mastery variables, were not asked at every wave but on discussion were felt to be potentially important in influencing capacity so were included. Overall, it was felt for most health locus of control and mastery would not vary significantly so the statements were treated as non-varying covariates. In addition, there were two measures to measure literacy: AH4 score (a standardised verbal and numeracy score) and maximal educational achievement by the age of 35 years (oldest age of the youngest cohort at completion of the study). Maximal educational achievement by age of 35 years was used as a measure of someone's **potential** educational achievement as a single variable, across the cohort (the alternative would have been to look at educational achievement at each wave but as anyone from the youngest cohort was only 15 years at baseline this would have introduced significant bias).

Table 8-5 Table summarising Community Capacity Variables

Variable	How Measured	Responses	Missingness
How do you feel about your area?	Looking at the faces scale which face shows best how you feel about living in the area?	Faces identified on scale 1-7 with 1 most satisfied	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2
Neighbourliness	Do you exchange small favours with the people who live near? I am thinking about things like leaving a key to let a repair man in?	Yes/No	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2, only asked regional sample W3
Walking in the dark	How do you feel about walking around the area after dark? Would you say that you…	Never do it in any circumstances, try to avoid it, if possible, do it but feel uncomfortable, have no worries about doing it	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2
Problem – vandalism	Around where you live would you say vandalism is a problem?	Serious problem, a minor problem, not a problem	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2
Problem – litter	Around where you live would you say litter is a problem?	Serious problem, a minor problem, not a problem	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2
Problem – assaults/ muggings	Around where you live would you say assaults/muggings are a problem?	Serious problem, a minor problem, not a problem	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2
Problem – burglaries	Around where you live would you say burglaries are a problem?	Serious problem, a minor problem, not a problem	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2
Problem – young people causing disturbance	Around where you live would you say young people causing disturbance is a problem?	Serious problem, a minor problem, not a problem	Only asked oldest cohort W1, and oldest and middle-aged cohorts W2

Table 8-6 Table summarising Treatment Burden Variables.

Variable	How Measured	Responses	Missingness
Number of Medications	Participants asked to list medications taking (prescribed and OTC)	Numerical	Asked across all cohorts and waves
Number of GP visits in the last year	How many times have you seen a GP in the last year? (surgery and home)	None, 1,2,3-5, 6 or more AND binary value created	Asked across all cohorts and waves
Number of hospital outpatient visits	Over the last 12 months how many times have you attended an out-patient clinic at the hospital?	Numerical	Asked across all waves and cohorts.

Socioeconomic status was measured using the Carstairs score which was developed in 1981 using Scottish census data (Brown D, 2022). This is an aggregate score that combines several markers of deprivation, giving a more nuanced and accurate measure of deprivation rather than using a proxy such as income or housing tenancy (Brown D, 2022, Scottish Government, 2016). It uses four variables (car ownership, male unemployment, overcrowding and social class) to create an area score of deprivation for postcode sectors (Brown D, 2022). It updates every 10 years based on new census data (Brown D, 2022). The Carstairs score for each participant's postcode was calculated at each data collection and the Carstairs's scores were used to divide the cohort into the recognised Carstairs DEPCAT categories from 1 the most affluent to 7 the most deprived, based on cut-offs from the 2001 census table.

Previous work (Katikireddi et al., 2017) using the WoS20-07 cohort created multimorbidity variables at each wave which were used for this study. LTCs were defined using the 40 conditions used in Barnett et al. (2012) seminal multimorbidity paper. Conditions were coded using RCGP morbidity classification (Royal College of General Practitioners, 1986) with codes double checked by clinicians. Conditions were coded as to whether they were physical or mental LTCs. Those with two or more of the forty identified LTCs were defined as having multimorbidity.

As the focus of this thesis is on multimorbidity the analysis was conducted on a cohort subset with multimorbidity. Of note this meant, for those who developed multimorbidity during the time they were part of this cohort study, some variables were from before they developed it. In addition, there were a small number of people who were coded with multimorbidity at earlier waves but not at subsequent ones. This was presumed to be because conditions were self-reported and the instances where this happened occurred when people had reported diagnoses such as migraine, or anxiety and depression whose symptoms periodically settle or improve. To ensure capturing everyone with multimorbidity the decision was made to conduct the analysis on a subset cohort that included anyone who had been coded with multimorbidity at any wave. A sensitivity analysis that treated multimorbidity as a time-varying covariate within the analysis showed minimal changes on effect size and confidence intervals (Appendix 15).

Chapter 4 discusses DAGs in detail and the rationale for using them in this work. A DAG was developed for each construct as a way of conceptualising how the independent variables (covariates) influenced outcomes. The mapping used known relationships from the literature, discussion with supervisors, various experts in this area, and a PPI representative. This allowed identification of any other key variables not included or measured. It also allowed a consensus amongst experts regarding potential confounders, mediators, and the relationships between them.

8.2.3 Statistical Analyses

Descriptive statistics were completed for each of the potential variables examining missingness and their distribution, as well as their individual relationship to socioeconomic deprivation, multimorbidity and mortality. Once the multimorbidity subset was created baseline characteristics of this cohort were examined.

Each of the potential groups of variables were examined to ensure no strong collinearity between them. Pattern of missingness within each of these groups of variables was reviewed and informed the strategy required to manage missing data both within and across the waves. Unadjusted Cox regression models were constructed for mortality, and multivariable regression models for self-reported number of nights in hospital in the last year, for each of the groups. The DAGs for each group were then used to inform adjustment of potential confounders.

An exploratory analysis of the potential moderating effect of SED was undertaken by splitting the original cohort into two subsets, as has been done previously (Buckton et al., 2015), by DEPCAT categories: Low (DEPCAT 1-3 -more affluent) and High (DEPCAT 4-7 -more deprived). The community construct models were then run on the subsets to explore if there was any suggestion of SED moderating associations.

8.3 Results

Table 8.7 demonstrates key descriptive statistics for the multimorbidity cohort at baseline compared to the main cohort.

Table 8-7 showing baseline characteristics of the Main cohort and the multimorbidity subset

	Main WoS20-07 Cohort at baseline	**Multimorbidity Subset at baseline**
Age, years - mean (SD)	36.2 (16.7)	37.94 (16.8)
Gender (n)		
Male	46.5% (2095)	46.1% (1722)
Female	53.6% (2415)	53.9% (2011)
Socio-economic Status(n)		
DEPCAT 1	5.0% (227)	5.04% (188)
DEPCAT 2	5.8% (262)	5.84% (218)
DEPCAT 3	8.9% (403)	8.79% (328)
DEPCAT 4	25.6% (1153)	25.85% (965)
DEPCAT 5	10.8% (488)	11.06% (413)
DEPCAT 6	21.7% (977)	21.48% (802)
DEPCAT 7	22.3% (1000)	21.94% (819)
Ethnicity (n)		
White	98.1% (4424)	98.5% (2216)
Other	1.1% (48)	0.8% (19)
Proportion smokers (n)		
Non-Smokers	48.6% (2190)	45.2% (1686)
Ex-Smokers	16.5% (743)	16.7% (622)
Current Smokers	34.7% (1565)	37.9% (1414)

As expected, the age in the multimorbidity subset was slightly older, and smoking rates were higher. Gender, SED, and ethnicity were similar between the two subsets at baseline. Due to the almost universal white ethnicity in the cohort, it was decided not to include this as a confounder in the analysis.

8.3.1 Direct Acyclic Graphs

The potential capacity variables were mapped to the BOTT constructs as discussed above. Daggity (2019) software was used to create DAGs (discussed in chapter 5) for each construct mapping their potential relationship to mortality. Potential confounder variables were added and their relationship to both potential variables and outcomes mapped. This served two purposes: firstly, it allowed mapping of assumptions behind the analysis from the outset, and it helped determine if potential confounders were indeed confounders or instead were mediators. The DAGs, and the suppositions made from them, were discussed with the supervisory team, experts in BOTT and a PPI representative. This ensured there were no key potential capacity factors omitted, and that there was broad agreement regarding the final DAGs produced. One variable challenging to classify as either a confounder or mediator was SED due to the very complex relationship between it, the outcomes and many of the variables and confounders of interest. Over several discussions with the statistical supervisor, it was decided to treat it as a confounder. The resulting DAGs are shown in Figures 8.2-8.6. Green nodes represent potential explanatory variables, dark grey dots are potential confounders. Light grey dots are important unmeasured capacity factors. As the known relationships between the variables are imputed the software identifies causal pathways (green), and bias pathways (pink) guiding what variables should be identified as confounders and adjusted for in the model.

Figure 8-2 DAG for impact of mobilising capacity factors and confounders on mortality utilising potential variables from the WoS 20-07 cohort

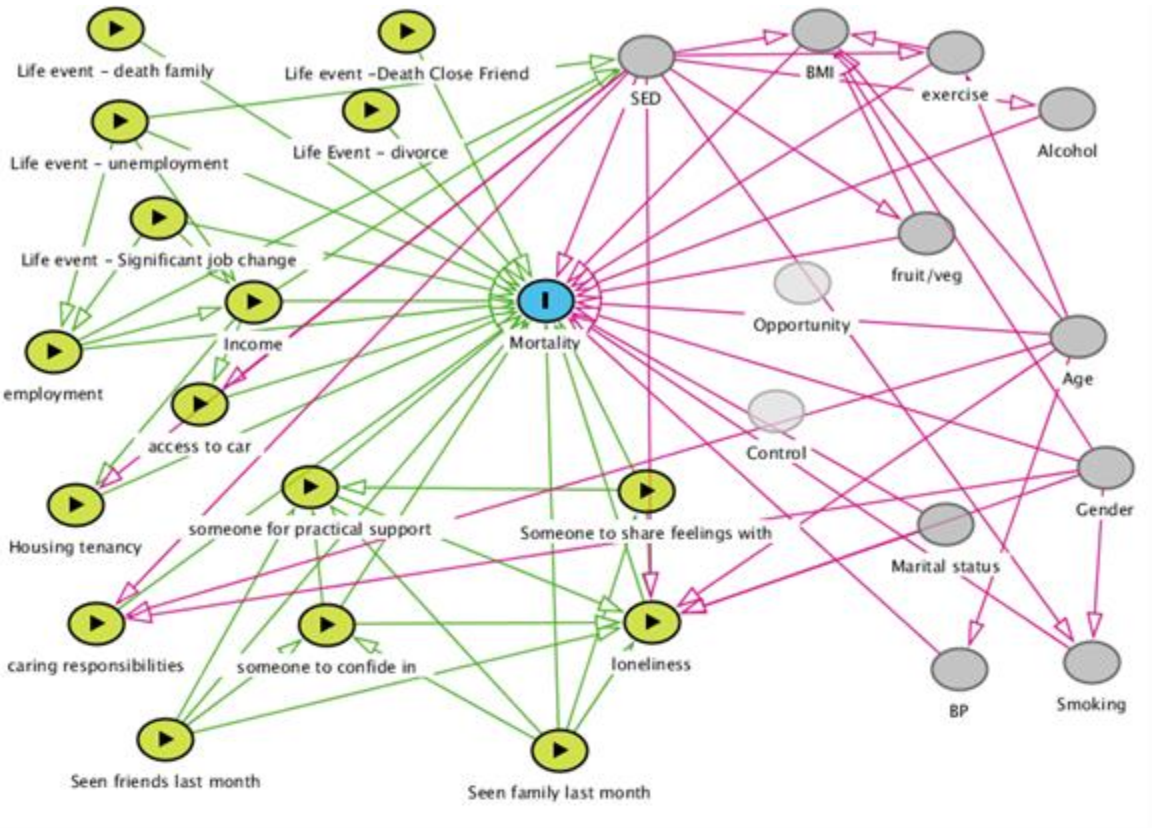


Figure 8-3 DAG for impact of expressing capacity factors and confounders on mortality utilising potential variables from the WoS 20-07 cohort

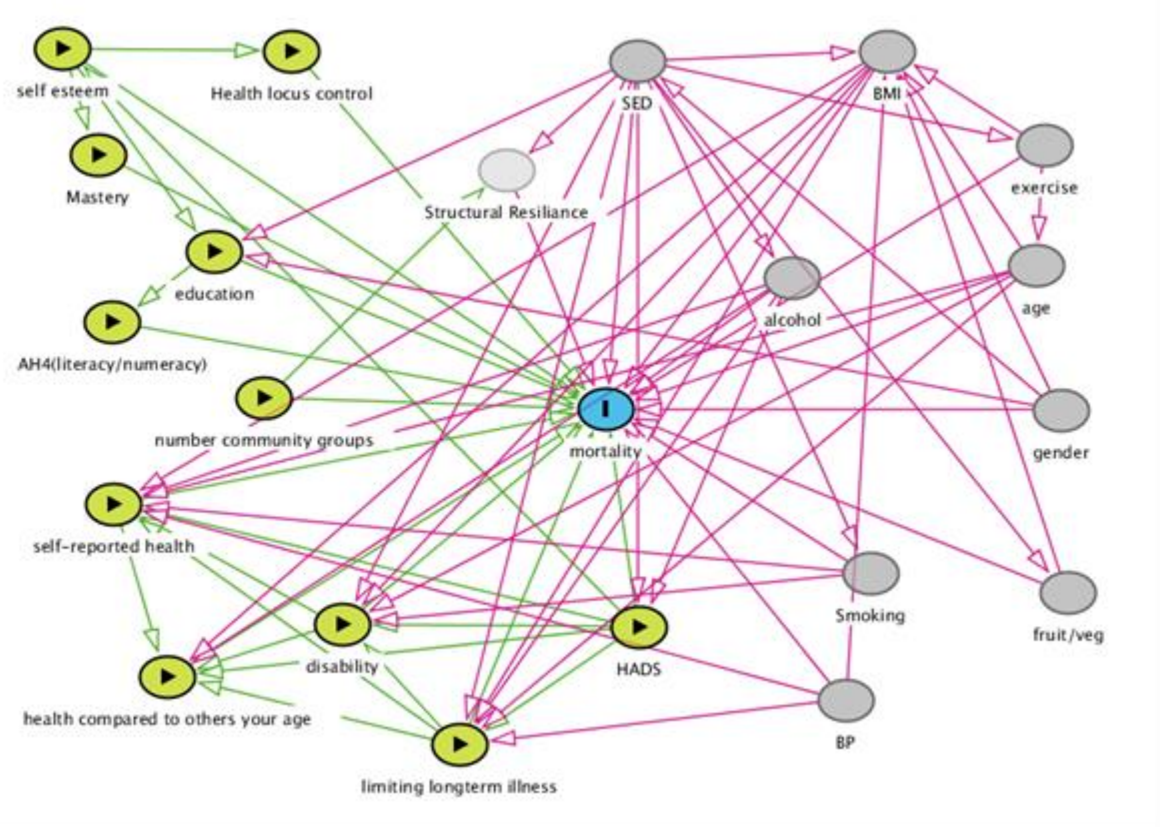
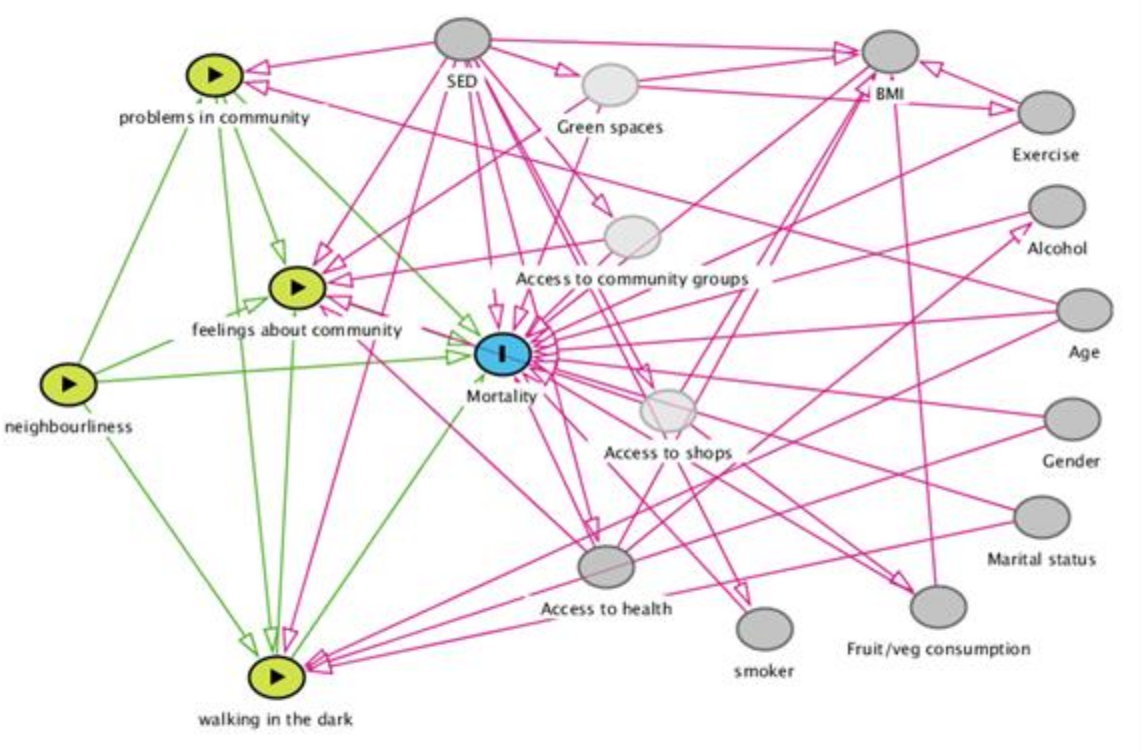
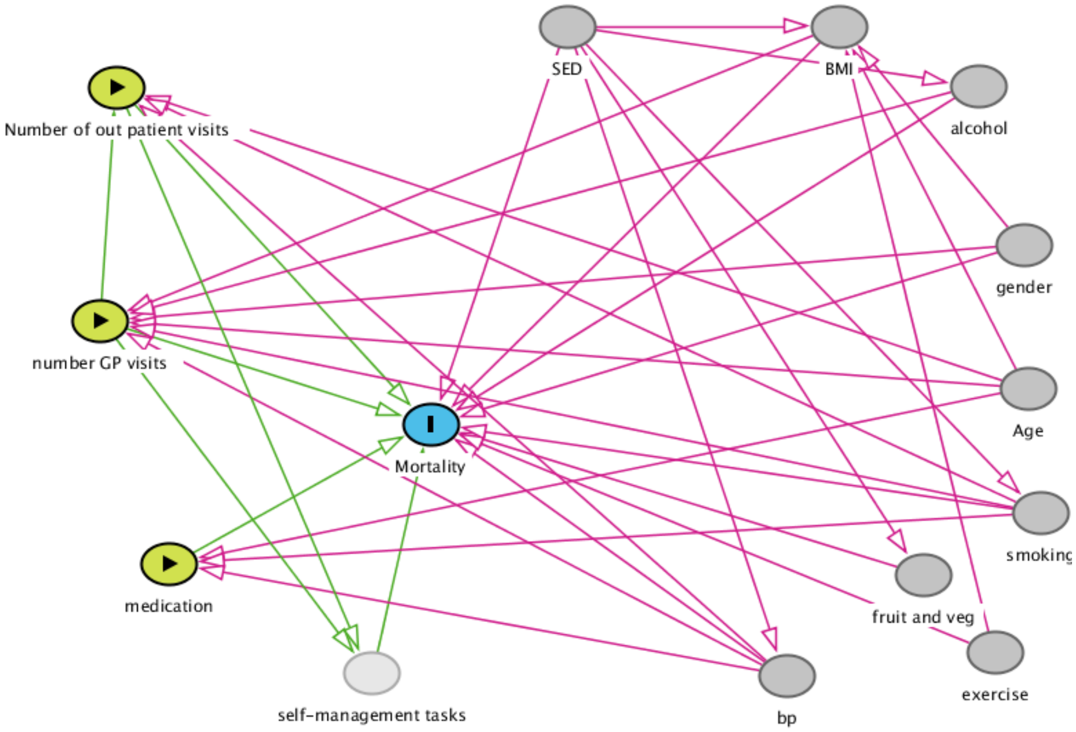


Figure 8-4 DAG for impact of community capacity factors and confounders on mortality utilising potential variables from the WoS 20-07 cohort



In discussion about potential important unmeasured factors the community capacity construct had the most identified. The cohort had limited information on access to community groups or shops, or the amount of green space within communities which could potentially be important.

Figure 8-5 DAG for impact of treatment burden factors and confounders on mortality utilising potential variables from the WoS 20-07 cohort



The treatment burden construct had the fewest available potential variables, and those used could be considered measures of illness burden as well as treatment burden.

8.3.2 Treatment Burden

The hazard ratios for mortality, and odds ratios for hospital admission (do not have time-varying covariates), for each construct are presented in the tables below. The tables show hazard ratio results from four Cox regression models. Namely:

- Baseline model presenting Hazard Ratio if only baseline values were used.
- Model 1: presents hazard ratios unadjusted for any potential confounders but adjusted for time-varying covariates.
- Model 2: Model one adjusted for age, sex, and SED
- Model 3: Model 2 adjusted for the remaining confounders

The tables show odds ratio results from three logistic regression models. Namely:

- Model 1: Odds Ratios unadjusted for any potential confounders
- Model 2: Model one adjusted for age, sex, and SED
- Model 3: Model 2 adjusted for the remaining confounders

Table 8-8 Demonstrating Hazard Ratio (baseline and time-varying covariates) of mortality in relation to the treatment burden constructs variables Unadjusted and Adjusted.

Variables	Hazard Ratio (95% Confidence Interval)			
	Baseline Model	Time Varying Covariates		
		Model1 (Unadjusted)	Model 2 (Adjusted for age, sex, and SED)	Model 3 (Adjusted for all confounders)[a]
Self-reported number of GP visits in the last year				
None	1	1	1	1
One	0.92 (0.51,1.65)	0.94 (0.71,1.25)	0.91 (0.68,1.22)	1.01 (0.75,1.35)
Two	0.61 (0.31,1.21)	0.79 (0.59,1.05)	0.81 (0.61,1.08)	0.91 (0.68,1.21)
Three to Five	0.57 (0.30,1.09)	0.93 (0.73,1.19)	0.90 (0.70,1.15)	0.99 (0.77,1.27)
More than six	0.82 (0.42,1.60)	1.18 (0.92,1.05)	1.13 (0.89,1.45)	1.24 (0.97,1.59)
Self-reported number of hospital outpatient visits in the last year				
None	1	1	1	1
One	1.35 (0.77,2.37)	0.80 (0.58,1.11)	0.88 (0.63,1.21)	0.93 (0.67,1.29)
Two	1.21 (0.58,2.52)	0.79 (0.56,1.10)	0.90 (0.64,1.25)	0.92 (0.66,1.29)
Three	0.99 (0.41,2.39)	0.83 (0.57,1.19)	0.93 (0.65,1.34)	1.01 (0.70,1.46)
Four or more	1.52 (0.81,2.84)	1.00 (0.75,1.34)	1.13 (0.85,1.50)	1.20 (0.90,1.61)
Number of medications	1.25 (1.10,1.43)**	1.09 (1.07,1.11)**	1.09 (1.07,1.11)**	1.09 (1.06,1.11)**

*p<0.05 **p<0.01

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

Table 8-9 Demonstrating Odds Ratio (unadjusted and adjusted) for self-reported hospital admission in the last year for the variables in the Treatment Burden construct

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)		
	Model 1 (Unadjusted OR)	Model 2 (Adjusted for sex, age, and SED)	Model 3 (Adjusted for all confounders)[a]
Self-reported number of GP visits in the last year			
None	1	1	1
One	1.54 (1.02,2.35)*	1.54 (1.02,2.35)*	1.64 (1.04,2.63)*
Two	1.68 (1.14,2.54)*	1.69 (1.14,2.55)*	2.02 (1.32,3.17)**
Three to Five	2.92 (2.07,4.24)**	2.90 (2.05,4.21)**	3.29 (2.24,4.99)**
More than Six	5.41 (3.85,7.82)**	5.34 (3.79,7.73)**	6.00 (4.10,9.09)**
Self-reported number of hospital outpatient visits in the last year			
None	1	1	1
One	4.43 (2.82,7.27)**	4.47 (2.84,7.35)*	4.27 (2.69,7.06)**
Two	6.66 (4.25,10.92)**	6.86 (4.37,11.25)*	6.86 (4.34,11.3)**
Three	9.05 (5.65,15.10)**	9.39 (5.86,15.67)**	9.02 (5.58,15.17)**
Four or more	6.62 (4.38,10.57)**	6.81 (4.50,10.87)**	6.64 (4.36,10.63)**
Number of medications	1.08 (1.06,1.10)**	1.08 (1.06,1.11)**	1.08 (1.06,1.11)**

*$p<0.05$ **$p<0.01$

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

The variables available to measure treatment burden were not specific as cohorts do not routinely collect in-depth information regarding the work of illness. In addition, measuring treatment burden as opposed to illness burden can be difficult. The variables measuring a proxy of treatment burden may also indicate a degree of illness burden; results must be interpreted with this in mind. Of note, for mortality the only significant association was with increasing numbers of medications. In contrast, all the variables were significantly associated with hospital admission, with a dose response relationship for GP visits and hospital admissions. For outpatient admissions this dipped for four or more outpatient visits, potentially suggesting that increased surveillance and care is protective.

8.3.3 Mobilising Capacity

Table 8-10 Demonstrating Hazard Ratio (baseline and time-varying covariates) of mortality in relation to the mobilising capacity constructs variables Unadjusted and Adjusted

Variables	Hazard Ratio (95% Confidence Interval)			
	Baseline Model	Time Varying Covariates		
		Model1 (Unadjusted)	Model 2 (Adjusted for age, sex, and SED)	Model 3 (Adjusted for all confounders)[a]
Equivalised Household Income	0.99 (0.99,1.00)	1 (1,1)	1(1,1)	1 (1,1)
Housing Tenancy				
Owner	1	1	1	1
Social Housing	1.27 (1.04, 1.54)*	1.62 (1.34,1.95)**	1.53 (1.26,1.85)**	1.39 (1.14,1.68)**
Private Rent	1.03 (0.51, 2.11)	1.32 (0.76,2.29)	1.37 (0.79,2.40)	1.23 (0.70,2.17)
Other	1.33 (0.76, 2.32)	1.21 (0.59,2.46)	1.28 (0.63,2.62)	1.28 (0.62,2.64)
Access to a car				
Yes	1	1	1	1
No	1.07(0.90, 1.28)	1.18 (0.99,1.41)	1.17 (0.98,1.4)	1.13 (0.93,1.36))
Employment Status				
Employed/self-employed	1	1	1	1
Full Time Education	1.44 (0.45, 4.59)	4.06 (0.94,17.51)	4.16 (0.95,18.17)	3.70 (0.83,16.52)
Carer/Housewife	1.01 (0.80, 1.27)	1.57 (0.99,2.47)	1.96 (1.23,3.11)**	2.00 (1.26,3.19)**
Retired	1.60 (1.12, 2.27)**	1.62 (1.13,2.32)*	1.66 (1.16,2.38)**	1.63 (1.14,2.33)**
Unemployed	1.58 (1.20, 2.08)**	2.39 (1.29,4.44)**	2.36 (1.27,4.38)**	1.83 (0.97,3.44)
Disabled	1.91 (1.51, 2.41)**	3.34 (2.32,4.83)**	3.40 (2.35,4.91)**	2.88 (1.98,4.19)**
Seen Family member in the last month?				
Yes	NA[b]	1	1	1
No		1.40 (0.58,3.42)	1.40 (0.58,3.40)	1.31 (0.54,3.17)
Seen Friend in the last month?				
Yes	NA[b]	1	1	1
No		0.56 (0.23,1.37)	0.56 (0.23,1.37)	0.61 (0.25,1.49)

Number of people you can rely on for practical support:				
None	Not Asked at baseline	1	1	1
Up to five		1.09 (0.8,1.48)	1.08 (0.79,1.47)	1.04 (0.76,1.43)
Five to ten		1.07 (0.74,1.54)	1.05 (0.73,1.51)	1.03 (0.71,1.50)
More than ten		1.27 (0.74,2.17)	1.08 (0.63,1.86)	1.07 (0.62,1.87)
Do you ever feel lonely?				
Never	1	1	1	1
Seldom	0.79 (0.59, 1.05)	0.70 (0.53,0.93)*	0.71 (0.53,0.95)*	0.68 (0.51,0.91)**
Occasionally	0.97 (0.78, 1.20)	0.87 (0.70,1.08)	0.93 (0.75,1.16)	0.89 (0.71,1.12)
Quite often	1.13 (0.85, 1.49)	1.44 (1.07,1.94)**	1.63 (1.20,2.20)**	1.74 (1.27,2.39)**
Most of the time	1.15 (0.75, 1.77)	0.89 (0.57,1.40)	0.95 (0.60,1.50)	0.93 (0.58,1.49)
Someone you can share your feelings with?				
All	1	1	1	1
Some feelings	0.98 (0.81, 1.17)	0.81 (0.65,1.00)	0.83 (0.67,1.03)	0.79 (0.64,0.99)*
A few feelings	0.84 (0.57, 1.24)	0.76 (0.54,1.06)	0.76 (0.54,1.06)	0.68 (0.48,0.95)*
Someone you can confide in?				
Very frequently	1	1	1	1
More often than not	0.69 (0.49, 0.96)	0.97 (0.66,1.44)	1.03 (0.7,1.54)	1.12 (0.75,1.68)
Occasionally	0.90 (0.69, 1.17)	0.96 (0.67,1.37)	1.08 (0.75,1.56)	1.17 (0.80,1.70)
Never	0.88 (0.67, 1.15)	0.89 (0.63,1.26)	0.97 (0.68,1.39)	1.02 (0.71,1.47)
Are you a carer?				
Yes	1	1	1	1
No	0.87 (0.74, 1.02)	0.70 (0.56,0.88)**	0.73 (0.59,0.92)**	0.72 (0.58,0.90)*
Divorced in the last year?				
Yes	1	1	1	1
No	0.71 (0.25, 1.95)	1.55 (0.9,2.68)	1.64 (0.95,2.84)	2.07 (1.11,3.87)*
Become unemployed in the last year?				
Yes	1	1	1	1
No	0.78 (0.32, 1.91)	0.71 (0.3,1.69)	0.62 (0.27,1.46)	0.71 (0.30,1.70)
Employment change in the last year?				
Yes	1	1	1	1
No	0.90 (0.41, 1.97)	1.11 (0.55,2.23)	1.1 (0.55,2.22)	1.2 (0.59,2.46)

Death in the family				
No	1	1	1	1
Yes	0.82 (0.55, 1.20)	0.83 (0.66,1.05)	0.82 (0.65,1.03)	0.79 (0.62,1.00)
Death of friend in the last year?				
No	1	1	1	1
Yes	1.56 (0.79, 3.08)	0.88 (0.7,1.1)	0.87 (0.69,1.09)	0.89 (0.71,1.12)

*p<0.05 **p<0.01

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

[b] At baseline every participant had seen someone from their family in the last four weeks, and only seven had not seen a friend, none of whom had died; therefore it was not possible to calculate any association.

Tenancy, employment, and loneliness are associated with mortality as individual factors, this analysis shows that association remains when other capacity factors are adjusted for. Divorce was also associated with mortality, but none of the other life events were. Identifying as a carer (but not a housewife) was protective, which has also been observed in the wider literature (O’Reilly et al., 2015). Having fewer people to share feelings with showed a slightly protective association but there was also no significant association with having someone to confide in, which is a similar question.

Another important finding is the impact of adjusting for time-varying covariates: capacity factors change over time and accommodating that change within the analysis changes the ratios compared to simply using a baseline measure. This is evident for the loneliness association which is only evident when time-varying covariates are used. Compared to never being lonely seldom feeling lonely is slightly protective, while quite often being lonely also shows a significant association with mortality.

Table 8-11 Demonstrating Odds Ratio (unadjusted and adjusted) for self-reported hospital admission in the last year for the variables in the mobilising capacity construct

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)		
	Model 1 (Unadjusted OR)	Model 2 (Adjusted for sex, age, and SED)	Model 3 (Adjusted for all confounders)[a]
Equivalised Household Income	1 (1,1)	1 (1,1)	1 (1,1)
Housing Tenancy			
Owner	1	1	1
Social Housing	1.23 (0.94,1.61)	1.19 (0.90,1.56)	1.20 (0.89,1.61)
Private Rent	1.29 (0.63,2.43)	1.25 (0.61,2.38)	1.30 (0.58,2.64)
Other	1.04 (0.29,2.91)	1.05 (0.29,2.95)	1.61 (0.44,4.63)
Access to a car			
Yes	1	1	1
No	1.06 (0.83,1.36)	1.04 (0.81,1.34)	1.00 (0.75,1.32)
Employment Status			
Employed/self-employed	1	1	1
Full Time Education	0.59 (0.03,3.11)	0.53 (0.03,2.84)	0.55 (0.03,3.02)
Carer/Housewife	2.07 (1.34,3.15)**	2.07 (1.32,3.20)**	1.74 (1.07,2.78)*
Retired	1.96 (1.51,2.55)**	2.20 (1.51,3.21)**	2.43 (1.61,3.69)**
Unemployed	0.98 (0.45,1.97)	1.02 (0.46,2.05)	1.12 (0.50,2.31)
Disabled	2.78 (1.91,4.03)**	2.89 (1.96,4.24)**	2.57 (1.67,3.95)**
Seen Family member in the last month?			
Yes	1	1	1
No	0.82 (0.47,1.52)	0.79 (0.46,1.48)	0.74 (0.42,1.41)
Seen Friend in the last month?			
Yes	1	1	1
No	0.99 (0.53,1.74)	1.02 (0.55,1.79)	1.14 (0.60,2.04)
Number of people you can rely on for practical support?			
None	1	1	1
Up to five	1.38 (0.85,2.34)	1.37 (0.84,2.33)	1.50 (0.88,2.72)

Five to ten	1.66 (0.97,2.94)	1.68 (0.98,2.98)	1.74 (0.96,3.28)
More than ten	1.7 (0.8,3.59)	1.75 (0.82,3.7)	1.60 (0.69,3.64)
Do you ever feel lonely?			
Never	1	1	1
Seldom	1.04 (0.72,1.46)	1.02 (0.71,1.43)	0.93 (0.62,1.35)
Occasionally	0.86 (0.63,1.16)	0.84 (0.61,1.13)	0.76 (0.54,1.05)
Quite often	1.38 (0.91,2.07)	1.36 (0.89,2.04)	1.15 (0.72,1.80)
Most of the time	2.00 (1.05,3.67)*	1.90 (1.00, 3.51)*	1.31 (0.61,2.68)
Have you someone you can share your feelings with?	1	1	1
All	0.88 (0.65,1.17)	0.88 (0.65,1.17)	0.85 (0.61,1.16)
Some feelings	0.67 (0.38,1.14)	0.70 (0.4,1.19)	0.62 (0.32,1.10)
A few feelings			
Have you someone you can confide in?			
Very frequently	1	1	1
More often than not	1.09 (0.63,1.9)	1.09 (0.63,1.92)	1.03 (0.57,1.9)
Occasionally	0.74 (0.45,1.25)	0.75 (0.46,1.26)	0.72 (0.42,1.27)
Never	0.83 (0.51,1.39)	0.84 (0.52,1.41)	0.8 (0.47,1.39)
Are you a carer?			
Yes	1	1	1
No	0.72 (0.54,0.94)*	0.72 (0.54,0.94)*	0.75 (0.56,0.99)*
Divorced in the last year?			
Yes	1	1	1
No	1.24 (0.56,2.5)	1.22 (0.56,2.47)	1.59 (0.64,3.78)
Become unemployed in the last year?			
Yes	1	1	1
No	0.92 (0.33,2.21)	0.95 (0.34,2.29)	1.05 (0.34,2.72)
Change in employment in the last year?			
Yes	1	1	1
No	0.6 (0.24,1.25)	0.6 (0.24,1.25)	0.52 (0.2,1.15)
Death in the family			
No	1	1	1
Yes	0.97 (0.67,1.38)	0.98 (0.68,1.4)	0.89 (0.59,1.32)

Death of friend in the last year?			
No	1	1	1
Yes	1.15 (0.82,1.59)	1.16 (0.82,1.61)	1.32 (0.92,1.85)

*p<0.05 **p<0.01

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

For hospital admissions, the only mobilising capacity relationship that is significantly associated with hospital admission is employment status of being a carer/housewife, retired (both may be associated with older age) or disabled. Once again identifying as a carer (without the housewife option) is protective, which may be expected as carer’s responsibilities may mean they are particularly likely to want to avoid hospital admission.

8.3.4 Expressing Capacity

The next two tables present the findings for the expressing capacity construct, this had by far the most variables because of the multiple locus of control, and mastery, questions, each with several options, in the WoS 20-07 questionnaire.

Table 8-12 Demonstrating Hazard Ratio (baseline and time-varying covariates) of mortality in relation to the expressing capacity constructs variables Unadjusted and Adjusted.

Variables	Hazard Ratio (95% Confidence Interval)			
	Baseline Model	Time Varying Covariates		
		Model1 (Unadjusted)	Model 2 (Adjusted for age, sex, and SED)	Model 3 (Adjusted for all confounders)[a]
Over the last 12 months would you say your health on the whole has been……				
Good	1	1	1	1
Fairly good	0.97 (0.68,1.38)	1.2 (0.89,1.61)	1.18 (0.88,1.59)	1.18 (0.88,1.59)
Not good	1.54 (0.84,2.84)	1.32 (0.87,2.01)	1.32 (0.87,2.01)	1.32 (0.87,2.01)
Would you say that for someone your own age your health in general is…				
Excellent	1	1	1	1
Good	1.12 (0.77,1.62)	1.01 (0.7,1.44)	0.98 (0.68,1.40)	0.95 (0.66,1.37)
Fair	1.91 (1.15,3.18)**	1.6 (1.03,2.49)**	1.51 (0.97,2.35)**	1.41 (0.90,2.20)
Poor	0.98 (0.40,2.37)	2.14 (1.18,3.89)**	2.12 (1.16,3.88)**	2.19 (1.18,4.06)**
Registered disability	Not asked at baseline			
No		1	1	1
Yes		1.62 (1.22,2.14)**	1.66 (1.25,2.21)**	1.7 (1.27,2.27)**
Depression				
No	1	1	1	1
Mild	0.91 (0.59,1.39)	1.18 (0.84,1.66)	1.09 (0.77,1.53)	1.05 (0.74,1.49)
Moderate	1.07 (0.5,2.29)	0.86 (0.49,1.51)	0.79 (0.44,1.39)	0.72 (0.4,01.29)
Severe	NA (NA,NA)	19.98 (3.65,109.51)**	18.58 (3.44,100.43)*	13.95 (2.35,82.78)*

Anxiety				
No	1	1	1	1
Mild	0.98 (0.72,1.33)	1.04 (0.78,1.38)	1.09 (0.81,1.45)	1.09 (0.81,1.47)
Moderate	1.20 (0.8,1.78)	0.84 (0.56,1.26)	0.89 (0.59,1.33)	0.86 (0.57,1.28)
Severe	0.81 (0.3,2.21)	0.53 (0.22,1.24)	0.58 (0.25,1.35)	0.65 (0.27,1.55)
AH4 score (literacy/numeracy measure)	0.98 (0.97,1.00)	0.97 (0.96,0.99)**	0.97 (0.96,0.99)**	0.97 (0.96,0.99)**
Rosenburg self-esteem score	0.99 (0.95,1.03)	0.97 (0.94,1.04)	0.98 (0.94,1.02)	0.98 (0.94,1.02)
Number community clubs involved in				
None	1	1	1	1
One	1.07 (0.79,1.47)	0.98 (0.75,1.27)	0.97 (0.75,1.27)	1.02 (0.78,1.33)
Two	1.08 (0.72,1.61)	0.71 (0.51,0.97)*	0.72 (0.52,1.00)	0.78 (0.56,1.09)
Three	0.74 (0.42,1.32)	0.95 (0.65,1.4)	0.99 (0.67,1.46)	1.06 (0.71,1.58)
Four or more	1 (0.47,2.14))	0.72 (0.44,1.19)	0.84 (0.51,1.40)	0.96 (0.56,1.62))
Not limited by LTC	1	1	1	1
Limiting longstanding illness	1.49 (1.17, 2.00)*	1.21 (0.94,1.57)	1.29 (1.00,1.68)*	1.33 (1.02,1.74)*
Maximum Educational Achievement by age 35				
None	1	1	1	1
Standard Grade	1.36 (0.87,2.13)	1.27 (0.88,1.84)	1.45 (1.00,2.1)*	1.51 (1.03,2.2)*
Apprenticeship	1.32 (0.93,1.89)	1.23 (0.91,1.68)	0.95 (0.68,1.33)	0.96 (0.68,1.34)
Higher	1.23 (0.74,2.04)	1.14 (0.72,1.82)	1.12 (0.7,1.81)	1.22 (0.76,1.98)
HND	2.09 (0.81,5.38)	2.76 (1.48,5.13)**	2.51 (1.31,4.8)**	2.69 (1.39,5.23)**
Degree	1.65 (1.02,2.67)*	1.58 (1.03,2.40)**	1.55 (1.00,2.39)*	1.56 (1.00,2.41)*
Health Locus of Control statements				
I have the power to make myself well				
Agree Strongly	1	1	1	1
Agree quite a bit	1.31 (0.82,2.08)	1.12 (0.77,1.64)	1.12 (0.77,1.65)	1.1 (0.75,1.63)
Agree a little	0.77 (0.47,1.26)	0.72 (0.48,1.07)	0.74 (0.5,1.10)	0.68 (0.45,1.02)
Disagree a little	0.8 (0.44,1.44)	0.65 (0.40,1.06)	0.64 (0.39,1.04)	0.54 (0.33,0.90)
Disagree quite a bit	1.04 (0.55,1.97)	0.81 (0.48,1.37)	0.78 (0.46,1.33)	0.68 (0.40,1.17)
Disagree a lot	0.58 (0.31,1.09))	0.62 (0.36,1.08)	0.68 (0.39,1.18)	0.53 (0.30,0.95)

I have no control over being ill				
Agree Strongly	1	1	1	1
Agree quite a bit	0.55 (0.30,1.02)	1.01 (0.60,1.70)	1.06 (0.62,1.82)	1.02 (0.59,1.77)
Agree a little	0.76 (0.42,1.37)	1.13 (0.68,1.88)	1.22 (0.73,2.05)	1.25 (0.74,2.14)
Disagree a little	0.91 (0.49,1.69)	1.44 (0.85,2.44)	1.55 (0.91,2.64)	1.63 (0.94,2.83)
Disagree quite a bit	0.77 (0.42,1.39)	1.21 (0.73,2.01)	1.3 (0.78,2.17)	1.26 (0.74,2.14)
Disagree a lot	0.92 (0.53,1.59)	1.27 (0.80,2.02)	1.31 (0.82,2.11)	1.32 (0.81,2.16)
Regular doctor visits reduce health				
Agree Strongly	1	1	1	1
Agree quite a bit	1.99 (1.11,3.57)*	1.72 (1.04,2.83)*	1.76 (1.06,2.90)*	1.77 (1.07,2.95)*
Agree a little	1.14 (0.68,1.91)	1.13 (0.73,1.75)	1.15 (0.74,1.78)	1.08 (0.69,1.69)
Disagree a little	0.66 (0.34,1.28)	0.83 (0.49,1.42)	0.88 (0.52,1.50)	0.83 (0.48,1.41)
Disagree quite a bit	0.77 (0.43,1.37)	0.95 (0.58,1.56)	1.02 (0.62,1.67)	0.98 (0.60,1.62)
Disagree a lot	0.88 (0.51,1.53)	0.91 (0.58,1.44)	0.92 (0.58,1.44)	0.88 (0.55,1.40)
Accidental happening influence health				
Agree Strongly	1	1	1	1
Agree quite a bit	1.23 (0.6,2.51)	1.5 (0.82,2.75)	1.55 (0.84,2.88)	1.48 (0.78,2.82)
Agree a little	1.06 (0.55,2.02)	1.18 (0.67,2.07)	1.24 (0.7,2.19)	1.12 (0.62,2.02)
Disagree a little	1.04 (0.53,2.05)	1.26 (0.71,2.26)	1.47 (0.82,2.64)	1.39 (0.75,2.58)
Disagree quite a bit	1.45 (0.74,2.84)	1.22 (0.68,2.17)	1.31 (0.73,2.35)	1.26 (0.68,2.33)
Disagree a lot	0.89 (0.47,1.7)	1.13 (0.66,1.96)	1.16 (0.67,2.01)	1.00 (0.56,1.80)
Only doctors can maintain health				
Agree Strongly	1	1	1	1
Agree quite a bit	1.68 (0.82,3.44)	1.41 (0.77,2.56)	1.36 (0.74,2.5)	1.31 (0.71,2.43)
Agree a little	0.64 (0.31,1.30)	0.66 (0.36,1.20)	0.70 (0.38,1.29)	0.60 (0.33,1.11)
Disagree a little	1.00 (0.48,2.07)	0.85 (0.46,1.58)	0.82 (0.44,1.54)	0.74 (0.39,1.38)
Disagree quite a bit	0.98 (0.48,1.99)	0.97 (0.53,1.77)	1.05 (0.57,1.92)	0.91 (0.49,1.68)
Disagree a lot	1.11 (0.56,2.2))	1.14 (0.64,2.04)	1.14 (0.64,2.04)	1.03 (0.57,1.84)
I am responsible for my health				
Agree Strongly	1	1	1	1
Agree quite a bit	0.98 (0.67,1.43)	1.08 (0.78,1.48)	1.11 (0.81,1.53)	1.09 (0.79,1.51)
Agree a little	1.49 (0.95,2.34)	1.70 (1.16,2.48)	1.66 (1.13,2.44)	1.69 (1.14,2.51)
Disagree a little	1.38 (0.76,2.52)	1.61 (0.99,2.62)	1.55 (0.94,2.54)	1.59 (0.96,2.63)
Disagree quite a bit	0.91 (0.40,2.04)	1.06 (0.54,2.10)	1.04 (0.53,2.04)	1.24 (0.62,2.46)

Disagree a lot	0.63 (0.29,1.35)	0.63 (0.31,1.27)	0.62 (0.3,1.26)	0.65 (0.31,1.36)
Others are responsible for my health				
Agree Strongly	1	1	1	1
Agree quite a bit	0.83 (0.43,1.61)	1.23 (0.7,2.16)	1.15 (0.65,2.03)	1.25 (0.7,2.24)
Agree a little	0.63 (0.34,1.16)	0.84 (0.49,1.43)	0.82 (0.47,1.43)	0.85 (0.49,1.49)
Disagree a little	0.87 (0.45,1.69)	1.42 (0.81,2.49)	1.36 (0.77,2.41)	1.65 (0.92,2.94)
Disagree quite a bit	0.59 (0.32,1.09)	0.77 (0.45,1.30)	0.73 (0.43,1.24)	0.76 (0.44,1.30)
Disagree a lot	0.84 (0.49,1.46)	1.03 (0.63,1.68)	1.07 (0.65,1.77)	1.15 (0.69,1.93)
It’s my fault when things go wrong with my health				
Agree Strongly	1	1	1	1
Agree quite a bit	1.41 (0.79,2.51)	1.30 (0.80,2.11)	1.23 (0.76,1.99)	1.25 (0.76,2.05)
Agree a little	1.19 (0.67,2.09)	1.38 (0.87,2.19)	1.34 (0.84,2.13)	1.35 (0.83,2.17)
Disagree a little	1.22 (0.69,2.16)	1.25 (0.77,2.02)	1.25 (0.77,2.03)	1.33 (0.81,2.17)
Disagree quite a bit	1.20 (0.68,2.14)	1.39 (0.86,2.26)	1.38 (0.85,2.23)	1.46 (0.88,2.42)
Disagree a lot	1.02 (0.58,1.78)	1.04 (0.65,1.67)	1.05 (0.65,1.70)	1.16 (0.70,1.90)
When I am ill, I let nature run its course				
Agree Strongly	1	1	1	1
Agree quite a bit	0.89 (0.49,1.59)	0.92 (0.58,1.45)	1.03 (0.65,1.63)	1.08 (0.67,1.74)
Agree a little	1.08 (0.64,1.83)	1.08 (0.70,1.65)	1.06 (0.69,1.63)	1.05 (0.67,1.64)
Disagree a little	1.00 (0.55,1.82)	1.11 (0.68,1.81)	1.12 (0.68,1.83)	1.13 (0.68,1.88)
Disagree quite a bit	1.24 (0.70,2.21)	0.94 (0.59,1.49)	0.98 (0.61,1.56)	1.06 (0.66,1.72)
Disagree a lot	1.36 (0.79,2.34)	1.02 (0.65,1.59)	1.01 (0.64,1.59)	1.06 (0.66,1.68)
When I’m health it’s because I am lucky				
Agree Strongly	1	1	1	1
Agree quite a bit	0.62 (0.32,1.17)	0.78 (0.46,1.32)	0.74 (0.43,1.26)	0.80 (0.47,1.37)
Agree a little	0.92 (0.48,1.74)	0.83 (0.49,1.39)	0.80 (0.47,1.36)	0.93 (0.54,1.6)
Disagree a little	0.76 (0.39,1.46)	0.80 (0.46,1.36)	0.79 (0.46,1.36)	0.85 (0.49,1.49)
Disagree quite a bit	0.83 (0.42,1.65)	0.81 (0.46,1.41)	0.81 (0.46,1.43)	0.92 (0.51,1.65)
Disagree a lot	0.96 (0.49,1.89)	0.91 (0.52,1.58)	0.92 (0.52,1.62)	1.04 (0.58,1.86)

Wellbeing depends on taking care of yourself				
Agree Strongly	1	1	1	1
Agree quite a bit	1.05 (0.62,1.76)	0.89 (0.58,1.38)	1.00 (0.64,1.56)	1.02 (0.65,1.60)
Agree a little	1.55 (0.93,2.6)	1.20 (0.79,1.84)	1.13 (0.73,1.73)	1.08 (0.69,1.67)
Disagree a little	1.67 (0.93,3)	1.25 (0.77,2.02)	1.19 (0.73,1.95)	1.14 (0.69,1.87)
Disagree quite a bit	1.44 (0.79,2.61)	1.18 (0.73,1.89)	1.17 (0.72,1.88)	1.18 (0.73,1.92)
Disagree a lot	1.24 (0.70,2.19))	0.80 (0.49,1.29)	0.81 (0.50,1.33)	0.77 (0.47,1.26)
Illness means you have not cared for yourself				
Agree Strongly	1	1	1	1
Agree quite a bit	1.11 (0.78,1.58)	1.09 (0.8,1.49)	1.09 (0.8,1.49)	1.04 (0.76,1.43)
Agree a little	0.98 (0.60,1.59)	1.08 (0.72,1.63)	1.13 (0.75,1.72)	1.23 (0.81,1.88)
Disagree a little	0.93 (0.37,2.36)	1.82 (0.92,3.59)	2.17 (1.09,4.34)	1.76 (0.86,3.59)
Disagree quite a bit	0.28 (0.10,0.83)*	0.65 (0.26,1.66)	0.70 (0.27,1.79)	0.64 (0.25,1.68)
Disagree a lot	1.27 (0.48,3.35)	1.97 (0.85,4.57)	1.82 (0.77,4.29)	1.96 (0.82,4.69)
Care from others helps me to get well				
Agree Strongly	1	1	1	1
Agree quite a bit	0.53 (0.32,0.88)**	0.5 (0.34,0.75)**	0.49 (0.33,0.73)	0.48 (0.32,0.72)**
Agree a little	0.75 (0.45,1.24)	0.66 (0.44,1.00)	0.62 (0.41,0.94)	0.62 (0.41,0.94)**
Disagree a little	0.45 (0.26,0.78)**	0.40 (0.25,0.63)**	0.40 (0.25,0.63)	0.40 (0.25,0.65)**
Disagree quite a bit	0.62 (0.36,1.07)	0.56 (0.35,0.89)**	0.51 (0.32,0.81)	0.53 (0.33,0.85)**
Disagree a lot	0.79 (0.45,1.4))	0.80 (0.5,1.29)	0.79 (0.49,1.29)	0.77 (0.46,1.27)
Illness is luck				
Agree Strongly	1	1	1	1
Agree quite a bit	0.61 (0.38,0.98)**	0.89 (0.61,1.3)	0.88 (0.60,1.3)	0.87 (0.58,1.29)
Agree a little	0.65 (0.40,1.04)	1.00 (0.68,1.49)	1.07 (0.72,1.59)	1.10 (0.73,1.64)
Disagree a little	0.76 (0.42,1.37)	1.32 (0.82,2.14)	1.49 (0.92,2.42)	1.45 (0.89,2.36)
Disagree quite a bit	0.59 (0.31,1.12)	1.01 (0.59,1.73)	1.03 (0.6,1.78)	0.98 (0.56,1.70)
Disagree a lot	0.68 (0.34,1.38)	1.00 (0.57,1.76)	0.97 (0.54,1.73)	0.93 (0.51,1.67)
Looking after myself keeps me healthy				
Agree Strongly				
Agree quite a bit	1	1	1	1
Agree a little	1.09 (0.65,1.84)	0.96 (0.62,1.48)	0.98 (0.63,1.52)	0.99 (0.63,1.56)

Disagree a little	1.35 (0.81,2.24)	1.25 (0.81,1.92)	1.2 (0.77,1.85)	1.24 (0.80,1.94)
Disagree quite a bit	1.28 (0.73,2.23)	0.95 (0.59,1.53)	0.91 (0.56,1.48)	0.82 (0.49,1.35)
Disagree a lot	1.67 (0.96,2.9)	1.16 (0.73,1.83)	1.11 (0.70,1.76)	1.12 (0.70,1.81)
	1.64 (0.93,2.89)	1.45 (0.90,2.33)	1.5 (0.92,2.44)	1.55 (0.93,2.56)
Doctor's orders keep me healthy				
Agree Strongly	1	1	1	1
Agree quite a bit	1.07 (0.51,2.26)	0.7 (0.37,1.31)	0.70 (0.37,1.31)	0.69 (0.37,1.32)
Agree a little	0.98 (0.49,1.96)	0.71 (0.4,1.27)	0.69 (0.39,1.23)	0.72 (0.40,1.31)
Disagree a little	0.65 (0.31,1.34)	0.62 (0.34,1.12)	0.62 (0.34,1.12)	0.58 (0.31,1.06)
Disagree quite a bit	0.67 (0.32,1.40)	0.65 (0.36,1.20)	0.63 (0.34,1.15)	0.62 (0.33,1.15)
Disagree a lot	0.81 (0.4,1.64)	0.82 (0.46,1.47)	0.84 (0.47,1.51)	0.89 (0.49,1.61)
I can usually stay healthy by taking good care of myself				
Agree Strongly	1	1	1	1
Agree quite a bit	1.06 (0.70,1.59)	1.09 (0.77,1.54)	1.1 (0.77,1.57)	1.23 (0.86,1.76)
Agree a little	1.57 (0.98,2.50)	1.09 (0.72,1.64)	1.12 (0.74,1.70)	1.20 (0.79,1.83)
Disagree a little	1.72 (0.91,3.27)	1.18 (0.68,2.03)	1.23 (0.71,2.13)	1.24 (0.71,2.16)
Disagree quite a bit	2.88 (1.22,6.76)*	1.30 (0.68,2.50)	1.37 (0.71,2.63)	1.57 (0.80,3.07)
Disagree Strongly	3.15 (1.04,9.56)	1.39 (0.57,3.37)	1.06 (0.42,2.64)	0.98 (0.38,2.56)
Following the doctors order to the letter is the way to stay healthy				
Agree Strongly	1	1	1	1
Agree quite a bit	1.00 (0.67,1.48)	0.89 (0.64,1.25)	0.87 (0.62,1.22)	0.80 (0.56,1.13)
Agree a little	0.82 (0.53,1.25)	0.97 (0.67,1.4)	1.03 (0.72,1.49)	1.01 (0.7,1.47)
Disagree a little	0.37 (0.2,0.7)**	0.58 (0.35,0.98)*	0.59 (0.35,0.99)*	0.57 (0.34,0.97)*
Disagree quite a bit	1.09 (0.58,2.04)	1.10 (0.66,1.82)	1.22 (0.73,2.04)	1.14 (0.67,1.95)
Disagree Strongly	0.41 (0.19,0.88)**	0.59 (0.32,1.08)	0.58 (0.31,1.08)	0.53 (0.28,1.00)
Mastery				
I have little control over what happens to me				
Strongly agree	1	1	1	1
Agree	0.57 (0.25,1.3)	0.50 (0.27,0.95)**	0.51 (0.27,0.98)**	0.51 (0.27,0.98)**
Disagree	0.55 (0.25,1.23)	0.47 (0.25,0.89)**	0.47 (0.25,0.90)**	0.47 (0.25,0.90)**

Strongly disagree	0.42 (0.17,1.04)	0.53 (0.26,1.05)	0.57 (0.28,1.14)	0.57 (0.28,1.14)
There is no way I can solve some of the problems I have				
Strongly agree	1	1	1	1
Agree	0.99 (0.44,2.23)	0.98 (0.52,1.84)	0.94 (0.49,1.81)	0.91 (0.47,1.79)
Disagree	0.93 (0.40,2.17)	1.02 (0.53,1.97)	0.93 (0.47,1.84)	0.86 (0.43,1.74)
Strongly disagree	1.23 (0.49,3.07)	1.06 (0.51,2.22)	0.97 (0.45,2.09)	0.83 (0.38,1.82)
There is little I can do to change many of the important things in my life				
Strongly agree	1	1	1	1
Agree	0.84 (0.33,2.15)	0.7 (0.34,1.43)	0.69 (0.33,1.43)	0.61 (0.29,1.27)
Disagree	0.86 (0.33,2.21)	0.64 (0.31,1.35)	0.62 (0.29,1.31)	0.56 (0.26,1.19)
Strongly disagree	1.06 (0.37,3.05))	0.60 (0.27,1.37)	0.55 (0.24,1.28)	0.49 (0.21,1.16)
Sometimes I feel helpless dealing with the problems in life				
Strongly agree	1	1	1	1
Agree	0.71 (0.28,1.82)	0.88 (0.43,1.79)	1.16 (0.56,2.42)	1.13 (0.54,2.37)
Disagree	0.72 (0.27,1.87)	0.99 (0.48,2.07)	1.17 (0.55,2.5)	1.22 (0.56,2.65)
Strongly disagree	0.73 (0.27,1.99)	0.98 (0.45,2.17)	1.06 (0.47,2.39)	1.08 (0.47,2.47)
Sometimes I feel I am pushed around in life				
Strongly agree	1	1	1	1
Agree	0.44 (0.17,1.11)	0.62 (0.29,1.35)	0.78 (0.35,1.71)	0.88 (0.4,1.94)
Disagree	0.79 (0.32,1.98)	1.07 (0.49,2.32)	1.29 (0.59,2.85)	1.38 (0.63,3.04)
Strongly disagree	0.38 (0.14,1.01)	0.77 (0.33,1.76)	1.05 (0.45,2.47)	1.19 (0.51,2.79)
What happens in the future depends mostly on me				
Strongly agree	1	1	1	1
Agree	1.19 (0.74,1.89)	1.03 (0.69,1.53)	0.98 (0.66,1.45)	1 (0.67,1.49)
Disagree	1.40 (0.80,2.45)	1.2 (0.75,1.92)	1.11 (0.69,1.77)	1.16 (0.72,1.88)
Strongly disagree	0.79 (0.36,1.75)	0.59 (0.30,1.18)	0.54 (0.27,1.08)	0.55 (0.27,1.11)
I can do just about anything I set my mind to				

Strongly agree	1	1	1	1
Agree	0.87 (0.53,1.41)	0.96 (0.63,1.45)	1.04 (0.68,1.59)	1.00 (0.65,1.53)
Disagree	0.78 (0.44,1.40)	0.90 (0.54,1.47)	0.93 (0.56,1.54)	0.82 (0.49,1.37)
Strongly disagree	1.14 (0.49,2.65)	1.17 (0.55,2.48)	1.27 (0.60,2.68)	1.28 (0.59,2.76)

*p<0.05 **p<0.01

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

In keeping with the mobilising capacity construct pre-existing known capacity variables such as disability and literacy levels were associated with mortality and remained significant even after adjusting for other capacity factors. Feeling your LTC limited life was also associated with mortality. Self-assessed health was not associated with mortality, although it was when people assessed their health compared to what would be expected for their age. Only severe depression was associated with mortality but the numbers in this category were small as evidenced by wide confidence intervals, so should be treated with caution.

There were a few isolated significant associations with mortality amongst the multiple health locus of control statements, many of which were only one positive association within a statement and these isolated associations should be interpreted with caution as given the number of variables in the model we would expect some to have a positive association by chance.

However, disagreeing with the statement “care from others helps me get well” appears protective (with only disagreeing a lot not significant). Meanwhile disagreeing with the mastery statement “I have little control over what happens to me” was protective, though the strongly disagreeing statement was also non-significant. This may suggest a protective association for those who are more independent or feel a higher sense of control over their LTCs.

Table 8-13 Table demonstrating Odds Ratio (unadjusted and adjusted) for self-reported hospital admission in the last year for the variables in the Expressing Individual Capacity construct

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)		
	Model 1 (Unadjusted OR)	Model 2 (Adjusted for sex, age, and SED)	Model 3 (Adjusted for all confounders)[a]
Over the last 12 months would you say your health on the whole has been……			
Good	1	1	1
Fairly good	2.68 (1.93,3.71)**	2.59 (1.81,3.71)**	2.82 (1.94,4.10)**
Not good	8.16 (5.1,13.06))**	6.96 (4.17,11.63)**	7.92 (4.64,13.54)**
Would you say that for someone your own age your health in general is…			
Excellent	1	1	1
Good	0.98 (0.69,1.40)	0.80 (0.53,1.22)	0.78 (0.51,1.2)
Fair	0.84 (0.52,1.35)	0.72 (0.42,1.23)	0.66 (0.38,1.16)
Poor	0.80 (0.42,1.54)	0.86 (0.42,1.75)	0.78 (0.37,1.64)
Registered disability			
No	1	1	1
Yes	1.92 (1.34,2.74)**	1.84 (1.26,2.67)**	2.00 (1.34,2.97)**
Depression			
No	1	1	1
Mild	1.00 (0.68,1.47)	1.01 (0.67,1.52)	1.10 (0.71,1.68)
Moderate	1.33 (0.73,2.37)	1.21 (0.64,2.24)	1.32 (0.69,2.51)
Severe	2.26 (0.17,31.88)	2.08 (0.14,33.99)	2.47 (0.07,51.52)
Anxiety			
No	1	1	1
Mild	0.98 (0.73,1.32)	1.02 (0.73,1.42)	1.00 (0.7,1.41)
Moderate	0.75 (0.50,1.11)	0.83 (0.53,1.27)	0.79 (0.5,1.23)
Severe	0.82 (0.39,1.65)	1.14 (0.53,2.39)	1.08 (0.49,2.3)
AH4 score (literacy/numeracy measure)	0.98 (0.97,1)	0.98 (0.97,1)	0.98 (0.97,1)
Rosenburg self-esteem score	1 (0.96,1.05)	1 (0.96,1.05)	1 (0.96,1.05)

Number community clubs involved in			
None	1	1	1
One	1.02 (0.75,1.4)	0.95 (0.69,1.32)	0.95 (0.69,1.32)
Two	1.54 (1.08,2.2)*	1.46 (1,20.11.0)*	1.46 (1.00,2.11)*
Three	0.88 (0.52,1.46)	0.87 (0.50,1.44)	0.87 (0.50,1.44)
Four or more	1.38 (0.79,2.34)	1.45 (0.81,2.53)	1.45 (0.81,2.53)
Not limited by LTC	1	1	1
Limiting longstanding illness	1.2 (0.93,1.55)	1.07 (0.81,1.44)	1.1 (0.82,1.48)
Maximum Educational Achievement by age 35			
None	1	1	1
Standard Grade	1.06 (0.73,1.51)	1.28 (0.85,1.91)	1.36 (0.89,2.05)
Apprenticeship	1.27 (0.92,1.75)	1.33 (0.9,1.97)	1.35 (0.89,2.04)
Higher	0.96 (0.59,1.53)	0.99 (0.56,1.69)	1.08 (0.6,1.89)
HND	0.93 (0.48,1.68)	1.42 (0.65,2.92)	1.68 (0.76,3.52)
Degree	0.81 (0.52,1.25)	0.86 (0.51,1.43)	0.94 (0.56,1.58)
Health Locus of Control statement			
I have the power to make myself well			
Agree Strongly	1	1	1
Agree quite a bit	1.01 (0.68,1.51)	0.99 (0.63,1.57)	0.97 (0.61,1.57)
Agree a little	0.72 (0.48,1.09)	0.73 (0.46,1.17)	0.75 (0.46,1.22)
Disagree a little	0.94 (0.58,1.53)	1.00 (0.58,1.74)	0.97 (0.55,1.73)
Disagree quite a bit	0.83 (0.47,1.44)	0.90 (0.47,1.70)	0.82 (0.42,1.59)
Disagree a lot	0.92 (0.51,1.61)	0.88 (0.45,1.68)	0.75 (0.37,1.49)
I have no control over being ill			
Agree Strongly	1	1	1
Agree quite a bit	0.93 (0.53,1.63)	0.79 (0.43,1.48)	0.87 (0.45,1.68)
Agree a little	0.77 (0.45,1.34)	0.71 (0.39,1.32)	0.78 (0.41,1.50)
Disagree a little	1.11 (0.63,1.95)	0.98 (0.53,1.85)	1.07 (0.55,2.09)
Disagree quite a bit	0.64 (0.37,1.12)	0.50 (0.27,0.93)*	0.49 (0.25,0.95)*
Disagree a lot	0.94 (0.57,1.57)	0.73 (0.42,1.30)	0.75 (0.41,1.39)
Regular doctor visits reduce health			
Agree Strongly	1	1	1
Agree quite a bit	1.66 (0.93,3.02)	1.8 (0.96,3.44)	1.74 (0.88,3.5)

Agree a little	1.42 (0.81,2.52)	1.51 (0.83,2.79)	1.57 (0.83,3.06)
Disagree a little	1.04 (0.57,1.92)	1.04 (0.53,2.05)	0.93 (0.46,1.93)
Disagree quite a bit	1.13 (0.63,2.06)	1.22 (0.65,2.32)	1.17 (0.59,2.35)
Disagree a lot	1.17 (0.67,2.07)	1.39 (0.76,2.59)	1.28 (0.67,2.50)
Accidental happening influence health			
Agree Strongly	1	1	1
Agree quite a bit	1.19 (0.61,2.35)	1.11 (0.54,2.35)	1.35 (0.63,2.99)
Agree a little	0.98 (0.53,1.86)	0.79 (0.40,1.58)	0.93 (0.46,1.95)
Disagree a little	0.94 (0.50,1.81)	1.01 (0.51,2.05)	1.21 (0.58,2.57)
Disagree quite a bit	1.00 (0.54,1.92)	0.86 (0.43,1.74)	1.01 (0.49,2.16)
Disagree a lot	1.57 (0.87,2.95)	1.67 (0.87,3.30)	1.70 (0.86,3.51)
Only doctors can maintain health			
Agree Strongly	1	1	1
Agree quite a bit	1.08 (0.51,2.29)	1.25 (0.56,2.81)	1.30 (0.57,2.98)
Agree a little	0.86 (0.42,1.77)	0.88 (0.41,1.95)	0.96 (0.43,2.17)
Disagree a little	1.59 (0.81,3.19)	1.72 (0.82,3.70)	1.90 (0.88,4.19)
Disagree quite a bit	1.46 (0.76,2.88)	1.93 (0.94,4.08)	1.93 (0.91,4.18)
Disagree a lot	1.46 (0.78,2.83)	1.70 (0.84,3.55)	1.72 (0.83,3.66)
I am responsible for my health			
Agree Strongly	1	1	1
Agree quite a bit	1.11 (0.81,1.53)	1.05 (0.73,1.50)	1.08 (0.74,1.58)
Agree a little	1.54 (1.05,2.26)*	1.25 (0.81,1.92)	1.25 (0.79,1.98)
Disagree a little	0.83 (0.46,1.45)	0.54 (0.27,1.03)	0.50 (0.24,0.98)*
Disagree quite a bit	1.65 (0.86,3.10)	1.58 (0.75,3.22)	1.41 (0.64,2.97)
Disagree a lot	0.84 (0.36,1.79)	0.71 (0.29,1.60)	0.77 (0.31,1.80)
Others are responsible for my health			
Agree Strongly	1	1	1
Agree quite a bit	1.14 (0.6,2.18)	1.47 (0.73,3.01)	1.80 (0.85,3.89)
Agree a little	1.2 (0.67,2.22)	1.26 (0.65,2.50)	1.72 (0.85,3.60)
Disagree a little	1.33 (0.72,2.53)	1.46 (0.72,3.00)	1.97 (0.94,4.24)
Disagree quite a bit	1.08 (0.6,1.99)	1.06 (0.55,2.11)	1.54 (0.76,3.23)
Disagree a lot	1.14 (0.66,2.03)	1.14 (0.62,2.15)	1.70 (0.88,3.40)
It’s my fault when things go wrong with my health			

Agree Strongly	1	1	1
Agree quite a bit	0.77 (0.45,1.33)	0.86 (0.48,1.58)	0.74 (0.40,1.37)
Agree a little	1.04 (0.62,1.76)	1.01 (0.57,1.81)	0.89 (0.49,1.61)
Disagree a little	1.01 (0.60,1.74)	0.93 (0.51,1.70)	0.75 (0.40,1.39)
Disagree quite a bit	1.2 0(0.72,2.04)	1.41 (0.80,2.53)	1.23 (0.68,2.24)
Disagree a lot	0.84 (0.50,1.45)	0.97 (0.54,1.75)	0.85 (0.46,1.57)
When I am ill, I let nature run its course			
Agree Strongly	1	1	1
Agree quite a bit	0.84 (0.51,1.41)	0.8 (0.45,1.41)	0.68 (0.38,1.23)
Agree a little	1.24 (0.77,2.00)	1.27 (0.75,2.15)	1.09 (0.64,1.89)
Disagree a little	1.31 (0.79,2.21)	1.23 (0.69,2.19)	1.15 (0.63,2.10)
Disagree quite a bit	1.08 (0.66,1.79)	1.1 (0.63,1.92)	0.95 (0.53,1.69)
Disagree a lot	1.24 (0.76,2.05)	1.2 (0.69,2.08)	1.08 (0.61,1.91)
When I'm health it's because I am lucky			
Agree Strongly	1	1	1
Agree quite a bit	0.68 (0.37,1.26)	0.79 (0.40,1.58)	0.71 (0.34,1.46)
Agree a little	0.64 (0.36,1.17)	0.76 (0.39,1.50)	0.67 (0.33,1.38)
Disagree a little	0.64 (0.35,1.18)	0.58 (0.29,1.17)	0.51 (0.25,1.08)
Disagree quite a bit	0.59 (0.32,1.09)	0.63 (0.32,1.29)	0.59 (0.29,1.24)
Disagree a lot	0.63 (0.34,1.17)	0.69 (0.34,1.40)	0.63 (0.30,1.33)
Wellbeing depends on taking care of yourself			
Agree Strongly	1	1	1
Agree quite a bit	0.99 (0.60,1.63)	1.19 (0.69,2.05)	1.21 (0.68,2.16)
Agree a little	0.77 (0.48,1.27)	0.85 (0.50,1.48)	0.93 (0.53,1.67)
Disagree a little	0.83 (0.48,1.42)	1.04 (0.57,1.89)	1.16 (0.62,2.19)
Disagree quite a bit	0.84 (0.50,1.41)	0.89 (0.50,1.59)	0.96 (0.52,1.78)
Disagree a lot	1.00 (0.59,1.70)	0.98 (0.55,1.76)	1.06 (0.57,1.96)
Illness means you have not cared for yourself			
Agree Strongly	1	1	1
Agree quite a bit	0.96 (0.7,1.32)	1.02 (0.72,1.45)	1.05 (0.73,1.51)
Agree a little	1.2 (0.79,1.82)	1.35 (0.84,2.18)	1.42 (0.86,2.32)
Disagree a little	1.07 (0.46,2.3)	1.02 (0.39,2.48)	1.03 (0.37,2.61)
Disagree quite a bit	0.64 (0.24,1.57)	0.66 (0.21,1.81)	0.64 (0.20,1.81)
Disagree a lot	1.34 (0.43,3.61)	1.28 (0.35,3.95)	1.37 (0.35,4.41)

Care from others helps me to get well			
Agree Strongly	1	1	1
Agree quite a bit	0.80 (0.50,1.28)	0.66 (0.40,1.10)	0.68 (0.40,1.16)
Agree a little	0.96 (0.60,1.54)	1.10 (0.67,1.82)	1.09 (0.65,1.85)
Disagree a little	0.93 (0.57,1.53)	0.86 (0.50,1.49)	0.82 (0.47,1.43)
Disagree quite a bit	0.99 (0.59,1.67)	0.81 (0.46,1.42)	0.78 (0.43,1.41)
Disagree a lot	1.21 (0.70,2.10)	1.09 (0.61,1.98)	0.98 (0.53,1.82)
Illness is luck			
Agree Strongly	1	1	1
Agree quite a bit	1.04 (0.68,1.60)	1.15 (0.72,1.87)	1.08 (0.66,1.78)
Agree a little	0.77 (0.50,1.20)	0.82 (0.50,1.35)	0.80 (0.49,1.34)
Disagree a little	0.79 (0.48,1.32)	0.76 (0.42,1.36)	0.73 (0.4,1.34)
Disagree quite a bit	0.93 (0.54,1.59)	0.98 (0.52,1.85)	0.97 (0.51,1.84)
Disagree a lot	0.90 (0.48,1.66)	1.01 (0.50,2.02)	1.07 (0.52,2.18)
Looking after myself keeps me healthy			
Agree Strongly	1	1	1
Agree quite a bit	1.11 (0.70,1.77)	0.93 (0.56,1.56)	0.90 (0.53,1.54)
Agree a little	1.32 (0.83,2.12)	1.19 (0.71,2.02)	1.12 (0.65,1.94)
Disagree a little	1.12 (0.68,1.87)	1.00 (0.57,1.78)	0.84 (0.46,1.52)
Disagree quite a bit	1.35 (0.84,2.21)	1.08 (0.63,1.88)	1.03 (0.59,1.83)
Disagree a lot	0.86 (0.50,1.46)	0.87 (0.48,1.57)	0.86 (0.46,1.59)
Doctor’s orders keep me healthy			
Agree Strongly	1	1	1
Agree quite a bit	0.85 (0.42,1.71)	0.68 (0.31,1.50)	0.69 (0.31,1.55)
Agree a little	0.97 (0.52,1.89)	0.93 (0.46,1.95)	0.83 (0.40,1.76)
Disagree a little	1.17 (0.62,2.30)	1.14 (0.56,2.39)	0.96 (0.46,2.08)
Disagree quite a bit	1.01 (0.53,1.98)	1.02 (0.50,2.16)	0.87 (0.41,1.87)
Disagree a lot	0.89 (0.47,1.73)	0.94 (0.46,1.97)	0.85 (0.41,1.82)
I can usually stay healthy by taking good care of myself			
Agree Strongly	1	1	1
Agree quite a bit	1.08 (0.76,1.54)	1.05 (0.71,1.57)	1.11 (0.73,1.68)
Agree a little	0.99 (0.65,1.51)	0.83 (0.51,1.35)	0.88 (0.53,1.45)
Disagree a little	0.82 (0.46,1.45)	0.85 (0.44,1.64)	0.95 (0.48,1.87)

Disagree quite a bit	0.91 (0.43,1.83)	0.79 (0.34,1.76)	0.88 (0.37,2.01)
Disagree Strongly	0.69 (0.23,1.87)	0.57 (0.16,1.80)	0.51 (0.13,1.75)
Following the doctors order to the letter is the way to stay healthy			
Agree Strongly	1	1	1
Agree quite a bit	1.02 (0.72,1.47)	1.03 (0.69,1.53)	0.99 (0.65,1.51)
Agree a little	0.87 (0.59,1.29)	0.85 (0.55,1.31)	0.79 (0.5,1.25)
Disagree a little	0.85 (0.53,1.36)	1.10 (0.64,1.87)	1.04 (0.59,1.81)
Disagree quite a bit	0.84 (0.49,1.44)	0.83 (0.45,1.50)	0.78 (0.41,1.45)
Disagree Strongly	0.76 (0.39,1.42)	0.57 (0.26,1.19)	0.54 (0.24,1.17)
Mastery Statements			
I have little control over what happens to me			
Strongly agree	1	1	1
Agree	1.53 (0.69,3.62)	1.64 (0.70,4.1)	1.96 (0.77,5.39)
Disagree	1.64 (0.74,3.92)	1.65 (0.71,4.15)	2.00 (0.79,5.53)
Strongly disagree	1.14 (0.49,2.87))	1.25 (0.50,3.32)	1.40 (0.53,4.08)
There is no way I can solve some of the problems I have			
Strongly agree	1	1	1
Agree	0.75 (0.36,1.61)	0.70 (0.33,1.55)	0.84 (0.37,1.98)
Disagree	0.63 (0.30,1.37)	0.53 (0.24,1.20)	0.63 (0.27,1.52)
Strongly disagree	0.76 (0.34,1.76)	0.48 (0.20,1.18)	0.54 (0.21,1.45)
There is little I can do to change many of the important things in my life			
Strongly agree	1	1	1
Agree	0.62 (0.28,1.42)	0.53 (0.23,1.28)	0.51 (0.21,1.28)
Disagree	0.64 (0.29,1.51)	0.57 (0.24,1.43)	0.57 (0.23,1.48)
Strongly disagree	0.76 (0.32,1.91)	0.69 (0.26,1.89)	0.58 (0.21,1.66)
Sometimes I feel helpless dealing with the problems in life			
Strongly agree	1	1	1
Agree	2.06 (0.89,5.12)	2.07 (0.8,5.72)	2.39 (0.88,7)
Disagree	2.78 (1.17,7.12)*	3.15 (1.18,9.01)*	3.17 (1.13,9.64)*

Strongly disagree	2.58 (1.02,6.99)*	2.93 (1.02,8.95)*	3.36 (1.12,10.9)*
Sometimes I feel I am pushed around in life			
Strongly agree	1	1	1
Agree	0.74 (0.35,1.64)	0.66 (0.30,1.54)	0.67 (0.29,1.66)
Disagree	0.74 (0.35,1.64)	0.61 (0.28,1.43)	0.63 (0.27,1.56)
Strongly disagree	0.74 (0.33,1.75)	0.66 (0.27,1.65)	0.70 (0.27,1.87)
What happens in the future depends mostly on me			
Strongly agree	1	1	1
Agree	0.85 (0.59,1.24)	0.78 (0.51,1.2)	0.67 (0.44,1.05)
Disagree	0.70 (0.44,1.11)	0.60k (0.35,1.01)	0.47 (0.27,0.81)**
Strongly disagree	0.56 (0.25,1.17)	0.64 (0.27,1.43)	0.66 (0.28,1.49)
I can do just about anything I set my mind to			
Strongly agree	1	1	1
Agree	0.97 (0.64,1.48)	0.80 (0.5,1.3)	0.87 (0.53,1.42)
Disagree	1.16 (0.69,1.95)	0.92 (0.52,1.65)	0.95 (0.53,1.73)
Strongly disagree	1.29 (0.54,2.99)	1.24 (0.49,3.05)	1.36 (0.52,3.47)

*$p<0.05$ **$p<0.01$

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

Disability was once again associated with admissions. In contrast to the mortality results, there was a strong association with self-assessed health and hospital admissions, while self-assessed health compared to others your age was not significant.

Again, there were a few isolated associations but unlike the mortality model there were no health locus of control statements that had more than one association. For the mastery statements a positive association with admission was seen in people who disagreed with the statement “Sometimes I feel helpless dealing with the problems in life”. There was also a protective association with disagreeing (although strongly disagreeing was NS) with the statement “what happens in the future depends mostly on me”. This suggests a potential increase in hospital admission in people who feel they have more control in their life.

8.3.5 Community Capacity

Table 8-14 Demonstrating Hazard Ratio (baseline and time-varying covariates) of mortality in relation to the community capacity constructs variables (Unadjusted and Adjusted.)

8Variables	Hazard Ratio (95% Confidence Interval)			
	Baseline Model	Time Varying Covariates		
		Model1 (Unadjusted)	Model 2	Model 3
Exchange Small Favours with those who live nearby	0.89 (0.76,1.04)	0.95 (0.81,1.12)	0.97 (0.83,1.14)	1.03 (0.88,1.21)
Yes				
No				
How do you feel about the area you live in (faces scale)				
1 Most Positive	1	1	1	1
2	0.98 (0.82,1.16)	0.89 (0.76,1.05)	0.84 (0.71,0.99)*	0.86 (0.73,1.02)
3	0.89 (0.72,1.09)	0.98 (0.81,1.18)	0.89 (0.74,1.08)	0.91 (0.75,1.10)
4	1.01 (0.75,1.36)	1.18 (0.90,1.55)	1.04 (0.79,1.37)	1.03 (0.78,1.35)
5	0.84 (0.54,1.31)	0.72 (0.46,1.14)	0.71 (0.45,1.12)	0.76 (0.48,1.21)
6	0.85 (0.47,1.53)	1.30 (0.80,2.10)	1.16 (0.71,1.88)	1.18 (0.72,1.92)
7 Most Negative	1.27 (0.82,1.95)	1.63 (1.08,2.47)*	1.60 (1.05,2.41)*	1.58 (1.04,2.39)*
How do you feel about walking around the area after dark? Would you say that you				
Never	1	1	1	1
Try to avoid	0.83 (0.65,1.05)	0.60 (0.48,0.73)**	0.61 (0.50,0.75)**	0.70 (0.57,0.87)**
Feel uncomfortable	0.86 (0.67,1.1)	0.64 (0.51,0.81)**	0.58 (0.46,0.74)**	0.66 (0.52,0.84)**
Have no worries	0.94 (0.78,1.14)	0.67 (0.57,0.78)**	0.53 (0.44,0.63)**	0.63 (0.53,0.76)**
Around the area you live would you say vandalism is a problem?				
Serious Problem	1	1	1	1
Minor Problem	0.83 (0.66,1.03)	0.95 (0.76,1.20)	0.97 (0.77,1.22)	1.03 (0.82,1.3)
No Problem	0.94 (0.74,1.2)	0.91 (0.71,1.18)	0.94 (0.73,1.21)	1.01 (0.78,1.3)

Around the area you live would you say litter is a problem?				
Serious Problem	1	1	1	1
Minor Problem	1.04 (0.83,1.29)	0.99 (0.81,1.21)	1.02 (0.84,1.24)	1.01 (0.83,1.24)
No Problem	0.99 (0.79,1.23)	1.10 (0.88,1.36)	1.13 (0.91,1.4)	1.12 (0.90,1.39)
Around the area you live would you say assaults are a problem?				
Serious Problem	1	1	1	1
Minor Problem	0.93 (0.72,1.2)	0.99 (0.76,1.31)	1.04 (0.8,1.37)	0.98 (0.74,1.29)
No Problem	0.76 (0.59,0.99)*	0.88 (0.67,1.15)	0.97 (0.74,1.28)	0.92 (0.70,1.21)
Around the area you live would you say burglaries are a problem?				
Serious Problem	1	1	1	1
Minor Problem	1.03 (0.86,1.23)	0.89 (0.72,1.10)	0.93 (0.75,1.15)	0.93 (0.75,1.16)
No Problem	1.13 (0.93,1.38)	1.01 (0.81,1.26)	1.07 (0.86,1.33)	1.05 (0.84,1.31)
Around the area you live would you say young people causing disturbances are a problem?				
Serious Problem	1	1	1	1
Minor Problem	1.2 (0.89,1.63)	0.96 (0.73,1.25)	0.98 (0.75,1.28)	1.01 (0.77,1.32)
No Problem	1.02 (0.76,1.35)	0.91 (0.70,1.19)	0.97 (0.74,1.27)	0.98 (0.75,1.29)

*p<0.05 **p<0.01

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

The results for the community constructs showed a significant association between feeling most negative about your community and increased hazard of death. In addition, compared to people who never walked around their community after dark all other potential answers had a protective association with mortality.

Table 8-15 Demonstrating Odds Ratio (unadjusted and adjusted) for self-reported hospital admission in the last year for the variables in the community capacity construct

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)		
	Model 1 (Unadjusted OR)	Model 2 (Adjusted for sex, age, and SED)	Model 3 (Adjusted for all confounders)[a]
Exchange Small Favours with those who live nearby			
Yes	1	1	1
No	0.96 (0.8,1.16)	0.95 (0.8,1.14)	0.96 (0.79,1.16)
How do you feel about the area you live in (faces scale) 1 Most Positive	1	1	1
2	1.14 (0.93,1.38)	1.16 (0.95,1.40)	1.17 (0.95,1.43)
3	1.28 (1.02,1.60)*	1.22 (0.98,1.51)	1.25 (0.99,1.58)
4	0.98 (0.69,1.38)	0.94 (0.66,1.32)	1.01 (0.70,1.44)
5	1.01 (0.60,1.64)	1.04 (0.63,1.66)	1.00 (0.58,1.65)
6	1.75 (0.99,2.96)	1.74 (1.00,20.91)*	1.96 (1.09,3.39)*
7 Most Negative	1.13 (0.63,1.95)	1.12 (0.62,1.91)	1.18 (0.64,2.08)
How do you feel about walking around the area after dark? Would you say that you			
Never	1	1	1
Try to avoid	0.71 (0.55,0.93)*	0.80 (0.61,1.04)	0.80 (0.6,1.05)
Feel uncomfortable	0.55 (0.41,0.73)**	0.69 (0.52,0.92)*	0.61 (0.45,0.83)**
Have no worries	0.63 (0.51,0.77)**	0.68 (0.54,0.86)**	0.71 (0.55,0.91)**
Around the area you live would you say vandalism is a problem?			
Serious Problem	1	1	1
Minor Problem	0.89 (0.68,1.17)	0.94 (0.72,1.22)	0.96 (0.73,1.27)
No Problem	0.89 (0.67,1.20)	1.02 (0.77,1.37)	0.99 (0.73,1.35)
Around the area you live would you say litter is a problem?			
Serious Problem	1	1	1

Minor Problem	1.03 (0.81,1.31)	1.02 (0.8,1.29)	1.01 (0.79,1.3)
No Problem	1.2 (0.93,1.55)	1.15 (0.89,1.48)	1.17 (0.9,1.53)
Around the area you live would you say assaults are a problem?			
Serious Problem	1	1	1
Minor Problem	0.59 (0.43,0.82)**	0.75 (0.55,1.02)	0.63 (0.45,0.87)**
No Problem	0.60 (0.44,0.82)**	0.72 (0.53,0.98)*	0.63 (0.45,0.87)**
Around the area you live would you say burglaries are a problem?			
Serious Problem	1	1	1
Minor Problem	1.19 (0.94,1.50)	1.09 (0.87,1.35)	1.14 (0.9,1.45)
No Problem	1.36 (1.08,1.73)*	1.21 (0.97,1.53)	1.26 (0.98,1.62)
Around the area you live would you say young people causing disturbances are a problem?			
Serious Problem	1	1	1
Minor Problem	1.08 (0.78,1.5)	1.12 (0.82,1.55)	1.20 (0.86,1.69)
No Problem	0.97 (0.71,1.34)	0.97 (0.71,1.33)	1.02 (0.73,1.44)

*$p<0.05$ **$p<0.01$

[a] Confounders: age, sex, SED, alcohol, exercise, fruit and vegetable intake, BMI, smoking, marital status, blood pressure

There was an association with a Likert score of 6/7 and increased odds of admission to hospital. Once again, what you feel about walking in the dark is associated with hospital admissions – although less strongly than mortality, with the “try and avoid” response not significant for hospital admissions. While concerns about problems in the community had no association with mortality, minor or no concerns regarding assaults in your community was protective compared to those for whom it was a serious problem.

8.3.6 Influence of Socioeconomic Status

The final analysis was an initial exploratory test of potential moderation of SED which split the cohort into high (more deprived) and low (more affluent) subsets. It was expected that the variables most susceptible to moderation by SED were the community factors, so it was decided to run the analysis on this construct. SED was taken out of the model and then the community capacity model was run on the two subsets. Table 8.16 demonstrates the outputs for mortality, and table 8.17 for hospital admissions.

Table 8-16 Demonstrating the hazard ratios for mortality for the whole data set and the high and low DEPCAT subsets

	Hazard Ratio for mortality (95% confidence interval)		
Variables	Whole dataset	Affluent subset (n=734)	Deprived Subset (n=3733)
Exchange Small Favours with those who live nearby			
Yes	1	1	1
No	1.03 (0.88,1.21)	0.92 (0.53,1.6)	0.98 (0.85,1.14)
How do you feel about the area you live in (faces scale)			
1 Most Positive	1	1	1
2	0.86 (0.73,1.02)	0.87 (0.58,1.29)	0.92 (0.78,1.08)
3	0.91 (0.75,1.1)	0.52 (0.27,0.97)*	0.97 (0.81,1.16)
4	1.03 (0.78,1.35)	1.12 (0.45,2.82)	1.03 (0.8,1.33)
5	0.76 (0.48,1.21)	0.57 (0.07,4.71)	0.70 (0.45,1.07)
6	1.18 (0.72,1.92)	4.61 (0.5,42.78)	1.22 (0.76,1.96)
7 Most Negative	1.58 (1.04,2.39)*	-	1.54 (1.06,2.25)*
How do you feel about walking around the area after dark? Would you say that you			
Never	1	1	1
Try to avoid	0.70 (0.57,0.87)**	0.89 (0.45,1.75)	0.65 (0.53,0.80)**
Feel uncomfortable	0.66 (0.52,0.84)**	0.86 (0.39,1.89)	0.62 (0.49,0.79)**
Have no worries	0.63 (0.53,0.76)**	0.77 (0.41,1.43)	0.66 (0.55,0.78)**
Around the area you live would you say vandalism is a problem?			
Serious Problem	1	1	1
Minor Problem	1.03 (0.82,1.3)	0.77 (0.31,1.92)	1.14 (0.93,1.40)
No Problem	1.01 (0.78,1.3)	0.66 (0.25,1.73)	1.18 (0.94,1.50)
Around the area you live would you say litter is a problem?			
Serious Problem	1	1	1
Minor Problem	1.01 (0.83,1.24)	0.64 (0.35,1.19)	0.96 (0.80,1.16)
No Problem	1.12 (0.9,1.39)	0.87 (0.47,1.61)	1.06 (0.87,1.30)

Around the area you live would you say assaults are a problem?			
Serious Problem	1	1	1
Minor Problem	0.98 (0.74,1.29)	0.85 (0.10,7.32)	0.91 (0.71,1.15)
No Problem	0.92 (0.7,1.21)	1.03 (0.13,8.51)	0.84 (0.66,1.06)
Around the area you live would you say burglaries are a problem?			
Serious Problem	1	1	1
Minor Problem	0.93 (0.75,1.16)	1.82 (0.74,4.49)	0.86 (0.71,1.04)
No Problem	1.05 (0.84,1.31)	2.1 (0.83,5.31)	0.92 (0.75,1.12)
Around the area you live would you say young people causing disturbances are a problem?			
Serious Problem	1	1	1
Minor Problem	1.01 (0.77,1.32)	-	1.10 (0.86,1.41)
No Problem	0.98 (0.75,1.29)	-	1.00 (0.79,1.28)

*$p<0.05$ **$p<0.01$

[a] Adjusted for age, sex, alcohol, exercise, fruit, and vegetable intake, BMI, smoking, marital status, blood pressure

Table 8-17 Demonstrating the Odds Ratio for hospital admission for whole dataset, and for the high and low DEPCAT subsets.

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)		
	Whole dataset	Affluent subset (n=734)	Deprived Subset (n=3733)
Exchange Small Favours with those who live nearby			
Yes	1	1	1
No	0.96 (0.79,1.16)	1.68 (0.92,3.29)	0.87 (0.71,1.07)
How do you feel about the area you live in (faces scale)			
1 Most Positive	1	1	1
2	1.17 (0.95,1.43)	1.10 (0.69,1.74)	1.23 (0.98,1.56)
3	1.25 (0.99,1.58)	1.42 (0.80,2.47)	1.26 (0.97,1.64)
4	1.01 (0.70,1.44)	0.61 (0.13,2.00)	1.09 (0.74,1.59)
5	1.00 (0.58,1.65)	-	1.11 (0.64,1.86)
6	1.96 (1.09,3.39)*	-	2.19 (1.20,3.85)**
7 Most Negative	1.18 (0.64,2.08)	-	1.21 (0.65,2.16)
How do you feel about walking around the area after dark? Would you say that you			
Never	1	1	1
Try to avoid	0.80 (0.60,1.05)	0.73 (0.35,1.58)	0.77 (0.57,1.04)
Feel uncomfortable	0.61 (0.45,0.83)**	0.42 (0.17,1.01)	0.63 (0.45,0.87)**
Have no worries	0.71 (0.55,0.91)**	0.76 (0.39,1.53)	0.68 (0.52,0.89)**
Around the area you live would you say vandalism is a problem?			
Serious Problem	1	1	1
Minor Problem	0.96 (0.73,1.27)	0.42 (0.15,1.27)	1.01 (0.76,1.36)
No Problem	0.99 (0.73,1.35)	0.44 (0.15,1.37)	1.07 (0.78,1.49)
Around the area you live would you say litter is a problem?			
Serious Problem	1	1	1
Minor Problem	1.01 (0.79,1.3)	1.99 (0.84,5.37)	0.93 (0.71,1.21)
No Problem	1.17 (0.9,1.53)	1.75 (0.71,4.84)	1.13 (0.85,1.5)

Around the area you live would you say assaults are a problem?			
Serious Problem	1	1	1
Minor Problem	0.63 (0.45,0.87)**	3.25 (0.45,73.11)	0.60 (0.43,0.85)**
No Problem	0.63 (0.45,0.87)**	3.21 (0.46,70.81)	0.59 (0.42,0.84)**
Around the area you live would you say burglaries are a problem?			
Serious Problem	1	1	1
Minor Problem	1.14 (0.9,1.45)	0.95 (0.52,1.80)	1.17 (0.90,1.52)
No Problem	1.26 (0.98,1.62)	1.16 (0.62,2.24)	1.28 (0.98,1.69)
Around the area you live would you say young people causing disturbances are a problem?			
Serious Problem	1	1	1
Minor Problem	1.20 (0.86,1.69)	0.82 (0.23,3.97)	1.27 (0.90,1.82)
No Problem	1.02 (0.73,1.44)	0.9 0(0.26,4.33)	1.03 (0.73,1.47)

*p<0.05 **p<0.01

[a] Adjusted for age, sex, alcohol, exercise, fruit, and vegetable intake, BMI, smoking, marital status, blood pressure

The first thing to note is that because this cohort was set up to explore health inequalities over time, it has a negative socio-economic deprivation skew with comparatively fewer numbers in the more affluent cohort. The small numbers for the feelings about community question in the affluent subset meant OR and HR were not able to be estimated by the estimators used in logistic and Cox regression modelling. In addition, in the affluent cohort there were very few who felt young people causing disturbances in their area were a problem with very small numbers of death meaning an association with confidence intervals 0-infinity was displayed in the statistics package output. The subset analysis showed the significant positive association with feelings about walking in the dark and concerns about assaults disappeared in the more affluent subset, while becoming stronger in the deprived subset for both mortality and hospital admissions.

8.4 Discussion

8.4.1 Summary of findings

This is the first time, to our knowledge, that any attempt has been made to try and measure the impact of capacity factors on mortality and hospital admissions. It has demonstrated that BOTT provides a structure to explore capacity variables and that capacity measures vary over time (not adjusting for this in the analysis could potentially over-estimate or miss associations) and could be the foundation for future work. The constructs allow the creation of models that allow the exploration of individual capacity factors, in relation to other capacity factors at a population level.

As well as expected associations between known individual factors such as literacy, housing tenancy or disability this work has also highlighted a potential association between the extent to which people feel they have control over their health and hospital admissions, although the exact relationship is not clear. Emotional support may also have an influence, with a slight protective association for people with less people to share feelings with, although no association was seen for whether people had someone to confide in. There was also a potential protective association with mortality for people who do not feel strongly that they require others to care for them, which merits further exploration.

In addition, community factors appear to be important, and the persistent strong association between feelings regarding walking in the dark and mortality and hospital admissions is an important finding. Finally initial exploratory analysis suggests that SED could be a potential moderator on these capacity factors which requires further investigation.

8.4.2 Findings within the wider literature

Capacity is an understudied construct, and at present there are no validated measures (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022). One potential suggested measure is the Patient Activation Measure which examines how “activated” patients are in terms of engagement with their care (Hibbard et al., 2004). However, while similar, it does not fully capture capacity which influences patient experience regardless of health service engagement (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022). Another suggestion is a measure of “flourishing” (VanderWeele, 2017), whose constructs align with some capacity constructs (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022). However, it has methodological weaknesses, and was based on a healthy population meaning its use on those with LTCs remains uncertain (K Boehmer, Gallacher K, Lippiett K, Mair F, May C, Montori V, 2022, VanderWeele, 2017). Neither measure therefore is really fit for purpose to measure capacity. Developing a validated measure that directly measures capacity constructs could be valuable to understand the impact of services and interventions on participant capacity.

8.4.3 Strengths and limitations

The significant strength of this exploratory analysis is that it is the first time, to our knowledge, anyone has attempted to measure capacity factors in relation to one another, rather than as individual factors. Due to the complex, multifactorial interactions of these factors this is a key strength. A further strength is that the analysis, and variable choices, is underpinned by a recognised theory.

Given this thesis's exploration of capacity in the context of SED, another strength is that unlike most research cohorts the WoS20-07 was recruited specifically to have as representative a population as possible, resulting in skewness in the socio-economic deprivation distribution. In addition, the cohort had four waves of data collection, as well as baseline factors, allowing the analysis to adjust for the change in capacity factors over time.

The key limitation of this analysis was the structure of the cohort itself. Different questions were asked across different waves making it difficult to measure the same variable over time, requiring proxies to be used in certain waves. Missing data was also a significant issue, one which is a known issue with most cohort populations, but in this context was made significantly worse by variation in questions asked across, and within, waves. In addition, the decision to use a postal questionnaire with different questions for a significant proportion of the cohort at wave 3 resulted in more missing data at this time point.

Furthermore, this was a complex cohort, with no list of available variables requiring manually going through the original questionnaires to clarify what was asked at each wave. It was only after the initial analysis that it became clear, for example, that the large numbers of social contacts questions asked in the earlier cohorts were replaced in the last two waves with one binary question. This meant that the influence of number, or type of social networks (shown in other literature (Koetsenruijter et al., 2016, Reeves et al., 2014) and the qualitative aspect of this thesis to be of importance) could not be explored in any depth, which is an important limitation.

Another limitation was that the proxy variables for treatment burden were also linked to illness burden as detailed information on workload was not collected. In recent years, several validated measures for treatment burden have been developed; incorporating these scores into the model would allow a proper exploration of this construct. The locus of control and mastery statements, which produced some positive associations, were each only asked in one wave, so it is not possible to determine whether such issues vary significantly across time.

A final limitation to be noted is the timing of the data collection – it measured data from the 1980s to 2007 and society has clearly changed in important ways since then. The cohort is 98.1% white, which was reflective of the West of Scotland at the start of data collection. Currently, the population in the West of Scotland is more ethnically diverse due to increased migration and Glasgow becoming one of the national Asylum hubs which is not reflected in this work. In addition, this cohort will not cover the impact of recent technology such as smart phones and health apps which were only just coming out as the cohort concluded. Therefore, it is important for future work to repeat this analysis on more modern cohorts, where the possibility of exploring digital health options (or indeed lack of access to them) could be explored.

8.5 Conclusion

This chapter describes a novel analysis that explores individual and community capacity constructs and their association with both mortality and hospital admission. As well as associations with expected factors, it demonstrated associations with mortality and hospital admissions and feelings about walking in the dark, the control people feel they have over their lives and whether people felt they needed others to care for them. Early exploratory work also suggests that SED has a moderating effect. Future work could build on these findings to explore better the role of SED, and to build a capacity measure that could inform the design and evaluation of future multimorbidity interventions and services.

Chapter 9 Introduction to Qualitative Work Package

9.1 Introduction

9.1.1 Aim

This chapter introduces the qualitative work package which generated large amounts of data. It describes the context of Drumchapel where the work was conducted, provides detail on how the methodological principles were applied, and the participants involved. Finally, it discusses the rationale behind the presentation of the results and the impact of the Covid pandemic on them.

9.1.2 Research Questions

The qualitative work packages sought to answer the following research questions:

- What are the key factors that impact capacity to self-manage in patients with multimorbidity living in areas of high socio-economic deprivation?
- How do community beliefs and resources enhance, or limit, capacity at an individual level to manage long-term conditions?

9.2 Description of Field

This section summarises the geographical context and describes the community groups, understanding of which informs interpretation of results.

9.2.1 The Field: Community of Drumchapel

Drumchapel is a geographically contained community, on the outskirts of the city of Glasgow, that experiences a high level of socio-economic deprivation (Scottish Government, 2016). The population of Drumchapel has shrunk over the last 40 years, something many of the residents commented on. It has also undergone a partial regeneration project, which has included the demolition of multiple tenements and the construction of new housing stock.

The time spent observing and gathering data allowed insight into how "*folk from the Drum*", as they often termed themselves, understand their community. During discussions they often referred to their area as a "scheme" (as in housing scheme), which will be the phrase used where relevant from now on. This word was commonly used to describe not only the area itself but was discussed in terms of *"scheme life"* – community experiences not unique to Drumchapel but shared with other [housing] schemes across Glasgow.

> 'cause we were a housing scheme, you know what I mean, Castlemilk, Easterhouse [communities across Glasgow], they all got the same stuff as we got. They were all looked at the same, oh housing scheme, all the rogues, and all up to no good. But that's not the way it is.
>
> Interviewee 24 (Male, 63)

In keeping with many post-industrial cities in the UK, Drumchapel has experienced the departure of heavy industry, including the loss of high skilled jobs.

> When…you've got to think, when this place…at one time it was 65,000 people living in it. I think it's 9,000 now but it's what it's like now. There was thousands that worked round about here. I mean, we left school we could get a job.
>
> Interviewee 16 (Male, 73)

The focus group members reminisced over the Drumchapel of their youth, sharing stories of working in factories. They mourned the loss of high-skilled job opportunities, lamenting that "*youngsters*" born after the closure of factories had no idea just how vibrant the community once was.

People also discussed the impact of the change in housing stock, with a shift from mostly tenement flats to *"front and back door"* houses. While the quality of these new houses was recognised, many longer-term residents felt younger generations lacked pride in their homes. They speculated the community had lost something of the communal spirit that tenement living encouraged:

> It's crazy, because everybody used to scream, they always wanted their own front door. As I say, it was all tenements. Because it was tenements, I stayed in before I was married, and after I was married. As I said, the social system was good with the tenements.

> Interviewee 20 (Male, 67)

As well as spending considerable time in the community groups, time was spent walking and driving round the community to become familiar with the physical space and built environment. Drumchapel is immediately adjacent to Bearsden: while Drumchapel is ranked in the most deprived quintile in Scotland, Bearsden sits comfortably in the most affluent quintile (Scottish Government, 2016). Of note the two communities fall into separate council areas (City of Glasgow and West Dunbartonshire) which means different providers of many community services. The marked differences, witnessed daily, in two communities literally right next to each other had a significant impact in how people from Drumchapel viewed, and defined, their community. For some it created a sense of deep injustice of how the scales were tipped against people like them:

> Bearsden is just there and somebody from Drumchapel, two of them going for the one job, and it’s not the building trade, it’s not in McDonald’s or anything like that, it’s something [better], they’ll not get it. They’ll not. And even they might be better qualified, but they’ll not get it.”
>
> Interviewee 16 (Male, 73)

There was a physical space (caused by the demolition of previous poor housing stock) between the two communities, with noticeable differences in housing style and stock moving from one community to the other. Even the signs welcoming you to the two communities differ visually in terms of upkeep. Figure 9.1 shows the poorly upkept signs welcoming people to the scheme and Glasgow city council as people drive from Bearsden.

Figure 9-1 Signs on entering Drumchapel from Bearsden

Meanwhile Figure 9.2 shows the cleaner, better upkept sign that welcomed people from Drumchapel into Bearsden.

Figure 9-2 Road sign coming out of Drumchapel into Bearsden

Figure 9.3 shows the centre of Drumchapel and one of the entrances to the shopping centre.

Figure 9-3 Picture of shopping centre in Drumchapel

When first built many remembered the shopping centre as a community hub, but it was now rundown, surrounded by dilapidated buildings and a large car park filled with potholes. Many residents described this area as *"a dump"* and an example of how the council valued their community.

> And…is the place run down? Yeah. Is it tired looking? Yeah. Still a lot of good people in it, type of thing. And it's just not had the investment or the proper investment that's needed.
>
> Interviewee 5 (Male, 59)

The shopping centre housed a pharmacy, a community fruit and vegetable shop and a charity run shop that served as a community hub. Many of the other shops were bargain based shops, which while *"better than nothing"*, were not necessarily the shops people would have chosen. There is also a large retail park at the edge of the scheme, which is widely used by multiple nearby communities, with several large shops including a supermarket. In the asset-based discussions this was recognised as a potential asset for those living near the *"bottom of the scheme",* but it was not for those who lived further away; unless they had their own transport it was not accessible.

Although supermarkets are not easily accessible for all residents in Drumchapel, the area is replete with fast food outlets and smaller convenience stores. Access to healthy food options is therefore curtailed, and indeed many of the local shops display large amounts of cheap, discounted, highly processed food. The obesogenic environment in areas of high SED, with clustering of take-aways and reduced access to affordable fresh food, is recognised (Townshend and Lake, 2017). Figure 9.4 demonstrates the distribution of shops on google maps, which highlights the patchy access for many living in Drumchapel (the shops out with the blue rectangles are all corner shops with limited fresh food and a high proportion of processed food). Meanwhile figure 9.5 demonstrates how takeaways are distributed across the community.

Figure 9-4 Distribution of shops across Drumchapel

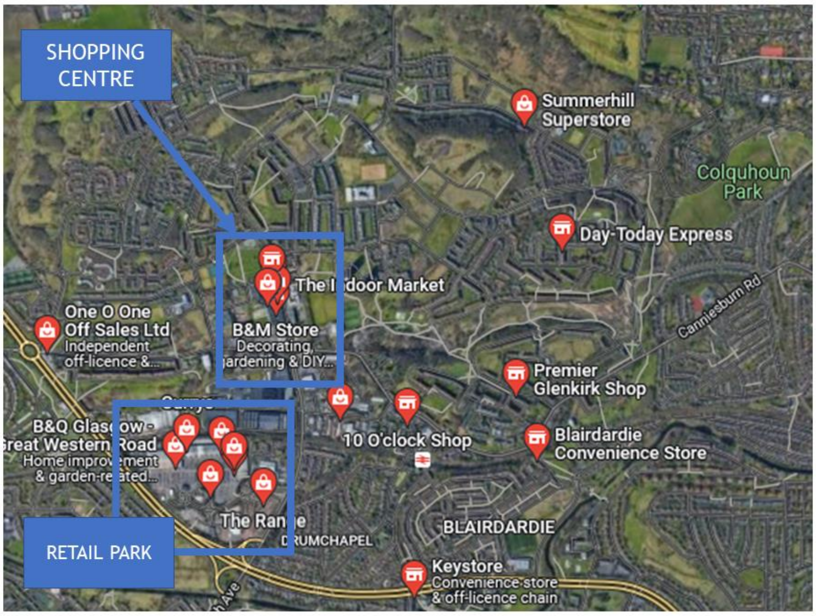


Figure 9-5 Distribution of takeaways across Drumchapel

9.2.2 The Community Groups

In sampling potential groups, those with a wide reach and serving a range of populations were prioritised, as was a willingness and ability to participate (certain groups were more impacted by covid restrictions than others).

9.2.2.1 3D Drumchapel (3D)

3D Drumchapel is *"a family support charity based in Drumchapel, who are committed to making a difference in the lives of children and their families in Drumchapel, Yoker & Knightswood by providing support, strengthening relationships and empowering families to make positive changes"*. It has been working in Drumchapel for almost 25 years and is highly valued by the community.

They offer several programmes including outdoor and school-based play groups for parents and children, intensive pre- and post-natal support, parenting support (individual and group) and a regular fortnightly "mums" night. In addition, they provide intensive family support, including home visits, food packages, toy packages as well as running a children's clothes and essentials bank (Bairn necessities). They have a dedicated small group of employed workers (many of whom have worked within the organisation for many years) supported by large numbers of volunteers. Volunteers are typically mothers who have who have benefited from the organisations' support in the past or members of the wider community seeking volunteer opportunities.

Many women continue attending events long after their children are grown up, and it was noticeable how multi-generational many of the events were. Services were well attended; specific activities reflected locally identified need. Initially there was concern this group would not allow observation of the experience of living with multimorbidity: attendees of parenting groups are traditionally younger. However, because of the multi-generational nature of this group, as well as the high prevalence of mental health issues, most of the participants attending experienced multimorbidity. In addition, this group managed to effectively engage socially vulnerable women allowing access to a hard-to-reach group.

9.2.2.2 Men Matter Scotland (MMS)

Men Matter Scotland was originally formed by men who wanted to tackle high rates of male suicide in Drumchapel. Informed by their lived experience, there was a frustration with current services which were thought not to adequately support men living in Drumchapel. Initially, with no funding, they "started with what they had” arranging football and walks at the park. As the group grew, they’ve partnered with various other third sector groups that help men with addiction issues, by taking them outdoors, going wild camping and teaching survival skills.

Men Matter have grown significantly and now have space above a pub (and it has a “pub feel”) which is open most days for any members. They offer a variety of activities from boxing to mindfulness. They host a regular talking group which was important for many of the attendees. It was often the first experience they had ever had of talking about their feelings and of hearing stories of other men like them. It often served as a springboard for men to go on to attend more structured mental health support such as CBT or mindfulness (offered by the group). For many the process to engagement with these therapies was slow and required several attempts.

The space houses a huge snooker table, a large TV and seating area, some smaller rooms (used when privacy is needed), a computer room, a small gym, a chill out room and a kitchen (pre-covid, people were able to go in and prepare food, now they have tea and coffee outside and either workers, or volunteers clean any cups). They also have a clothes bank, with toiletries, for men that need it. The support workers deal daily with “referrals” – people brought by relatives, or who self-refer, who need acute crisis support. There are no restrictions on referrals, the support workers’ ethos is to help and support as required.

Membership is open but participants must be willing to sign up to the behaviour code. The group aims not to exclude anyone; the code is clear and self-enforced by the men themselves. This self-enforcement helps significantly, as does the large number of volunteers with lived experience of addiction who are quick to challenge drug seeking. On the rare occasion someone turns up under the influence they are politely asked to leave and come back sober. During the observation period it was clear the group was “owned” by its members, who in turn work hard to protect it and the people who attend.

9.2.2.3 Growchapel (GC)

Growchapel is a community garden officially launched in November 2021. Unlike the other projects this was a new, council-led initiative so it allowed observation of a group as it started and developed. It was the only project not created by community members. However, there is a clear plan for the council to hand its running entirely over to the community itself, with a history of a similar approach in other areas of Glasgow. Its inception was prompted by community consultation on how to best use a piece of wild land, between two areas of housing that experienced significant anti-social behaviour. This led to the suggestion of a community garden, and it was developed with input from longstanding key community stakeholders. It had some local buy in, although some members of the other organisations and interviewees were ambivalent whether it would benefit them or the wider community. It also appeared that a proportion of the community were not aware of the garden. It is hard to know how much of this was impacted by it starting during the covid pandemic.

The plot-holders were all based in the community, with a community-based waiting list. There are also several larger community group plots, as well as a communal area which it is hoped will be used by the wider community for outdoor events, with plans to install an outdoor pizza oven. During data collection Growchapel was in its infancy, it may be that in time the community garden, becomes more established and viewed as an asset for more than just the plot holders.

9.2.2.4 Drumchapel Cycle Hub (DCH)

A local cycling-based initiative, affiliated to cycling UK, the cycle hub was started and run by a local resident – herself described as a community asset in one of the workshops. The physical context and setting were important:

> I found this fascinating – essentially the hub is two trade containers sitting together at the side of one of the busy roads of Drumchapel between the sports centre and the swimming pool. There are a lot of key buildings nearby including the shopping centre but most of them look quite tired and in some cases dilapidated. The hub however stands out. Coloured wood panelling has been put up on the outside of the containers where a smart beautiful wooden sign (Drumchapel cycle hub) sits on top of it. It looks good, welcoming, up to date and

> modern – in contrast with the surrounding area and signs which look like they have been barely upkept at best. There is nice decking round the side that looks over the small green area and sports courts behind the hub. There are LOADS of bikes, I don't know much about bikes, but they all seem of excellent quality and even while I was there, there was ongoing work on the upkeep of them."
>
> Fieldnote Cycle Hub 16th June 2021

The cycle leaders worked hard to coach, encourage, and challenge each person from absolute beginners to those managing the lead cycles. In addition, regular attendees took an active role encouraging those just starting, creating a supportive atmosphere.

Although felt to be rooted in Drumchapel this was the one group that attracted people from out with Drumchapel (likely a sign of its success). Unlike other sports groups in the community that were felt to be "parachuted in", the consensus was this group served the people of Drumchapel and was a significant asset.

9.3 Methods

An ethnographically informed approach was considered most appropriate to answer the research questions and a variety of methods including participant observation, in-depth interviews, focus groups and participatory research methods were utilised. Ethical approval was obtained through the University of Glasgow MVLS ethics committee [Project No: 200190093] in February 2020; the approval applied to the components of the study where participants were recruited via local community groups (participant observation and the asset-based workshops). Ethical permission for the in-depth interviews and focus groups, with participants recruited via GP practices, was obtained from the West Midlands Solihull Research Ethics Committee [IRAS Project ID 272255] in April 2021 (Appendix 7). Due to difficulties reaching our target sample size an amendment to the original request, to allow community links workers to recruit participants was granted in April 2022 [IRAS Amendment Number AM01 GN20HS047].

9.3.1 Recruitment

Existing contacts from Glasgow University, and Glasgow Centre for Population Health, provided initial introductions to key stakeholders within Drumchapel, who in turn introduced and provided contacts to other local community groups. As discussed in chapter 5, due to the pandemic participant observation was restricted to four groups to allow continuous relationships to be built with participants and ensure an adequate depth of data collection. Four groups serving different parts of the Drumchapel community consented to participate: Men Matter Scotland (MMS), 3D Drumchapel (3D), Growchapel (GC) and Drumchapel Cycle Hub (DCH). During the project relationships were built with participants in all four groups, and with their wider leadership teams.

NHS Research Scotland (NRS) Primary Care Team assisted with recruitment of interviewees, and three GP practices in the Drumchapel area agreed to participate. A list of potential participants was generated for each practice by the NRS team which was reviewed by one of the GPs to ensure all were suitable to be contacted. 357 Invitations packs including written information about the study, were sent to potential participants who then contacted the main researcher if interested (Appendix 4 and 5). A total of 25 participants were recruited for the in-depth interviews. The inclusion and exclusion criteria appear in table 9.1.

Table 9-1 Summary of Inclusion and Exclusion Criteria for Interviews

Inclusion Criteria	• Aged over 18 • Experiencing three or more long-term conditions • Resident of Drumchapel for at least the past 18 months. *
Exclusion Criteria	• Participants who lack capacity to consent • Participants who do not speak English

**While reasonable efforts were made to ensure people lived in the area, it did not become apparent until the end of two interviews that two participants had since moved to a nearby area. This was discussed with the project supervisors: both participants had grown up in Drumchapel, with most of their friends and family there, and this was where most of their socialising occurred. The criteria had been set to ensure interviews were carried out with people who had local links. As they both did, and their responses were relevant to the project, their transcripts were included.*

Informed consent was obtained from each participant and interviews took part via telephone, or in person. Interviews 1-9 took part during the second national lockdown and so were all by phone, the remaining interviews took place as restrictions were relaxed and so were by phone, or in participants home, as per the participant’s preference.

Both 3D and MMS, also agreed to participate in two asset-based workshops (ABWs). ABW participants were recruited from the 3D fortnightly “mum’s night” group that had been regularly attended, and from the wider membership of MMS; 5 were recruited for the 3D workshop, and 4 for the MMS one. A focus group was conducted at the end of the data collection period. All original interviewees were invited;11 consented to participate in the focus group, but only 4 were ultimately able to attend.

9.3.2 Data Collection

9.3.2.1 Participant Observation

The four community-based organisations were visited repeatedly (Table 9.2), to allow a deep understanding of the organisation and their membership. The groups gave informed consent for observation (consent form Appendix 6), and group leaders checked with all the participants they were happy for the researcher to be present at each session. Observation involved a range of activities including, craft activities at mum’s night with 3D, helping at an allotment at Growchapel, guided cycle rides with Drumchapel cycle hub, and playing snooker at MMS. Relationships were built and strengthened with participants over time. Detailed field notes were written as soon as possible after each observation using a structured form (Appendix 8). Relationships were also built with some of the group leaders, who also gave their time to discuss their organisation’s ethos. Several group leaders also sense checked themes as the analysis progressed. Although the project focused on four groups to allow a depth of data collection, small amounts of time were spent in other organisations and with community stakeholders, before and after lockdown, as feasible. Table 9.2 summarises the different types of evidence collected.

Table 9-2 Table summarising types of evidence collected from participant observation part of the project.

Type of Information	Organisation	Number	Hours Involved
Field Note – Stakeholder Interview	Multiple	18	16
Field Note – Participatory Observation	3D Drumchapel	17	48
Field Note – Participatory Observation	Men Matter Scotland	10	30
Field Note – Participatory Observation	Drumchapel Cycle Hub	5	20
Field Note – Participatory Observation	Growchapel	6	20
Field Note – Place	Time spent exploring and reflecting on built environment of Drumchapel	4	4
Supplementary Community Information	Different reports suggested to read by stakeholders	15	4

9.3.2.2 In-Depth Interviews

An initial topic guide was developed based on BOTT, which was adapted iteratively as the interviews progressed (Appendix 9). Examples of additions included perceptions of changes in Drumchapel over time and how this may have impacted the wider community identity, work and identity derived from work, and exploring the experience of stigma and how this may have influenced interactions with statutory services (including health).

The interviews were carried out in three cohorts, related to when the different practices were able to accommodate the NRS team. Data analysis was conducted iteratively during this period, and a broad thematic analysis was completed on the first 21 interviews, at which point data saturation was reached. The topic guide for the remaining 4 interviews included an exploration of the emerging themes.

Field notes were completed immediately after each interview, and basic demographic and health data were collected for each participant: age, sex, number of medical conditions and medications (often revealing conditions patients had forgotten about). All interviews were audio-recorded, transcribed, and anonymised.

9.3.2.3 Asset Based Workshops and Focus Groups

The ABWs followed the outline illustrated in Appendix 11. Two workshops were carried out (one with a group from MMS and one from 3D) and utilised a variety of activities that allowed an in-depth discussion regarding the community and what participants viewed as assets. Key findings from the work were then presented before holding a facilitated discussion regarding the asset-based activity and participants thoughts on the findings (topic guide in Appendix 11). This discussion was audio-recorded, anonymised and transcribed.

A focus group (topic guide Appendix 12) was conducted with interviewees who consented to take part. Initial findings were presented and then discussed by the participants allowing an in-depth exploration of whether the results resonated with them. The conversation was audio-recorded but unfortunately, due to a dictaphone malfunction, it was not able to be transcribed. Extensive field notes that had already been taken were expanded as soon as this came to light to document the key points that were brought up and discussed by the participants.

9.3.3 Data analysis

As discussed, while it was expected this work would produce results relevant to BOTT it was also expected that there could be other important issues identified. To ensure all this data was captured an initial broad inductive thematic analysis was conducted (Braun and Clarke, 2006) and applied to all data sets. Broad thematic analyses of the field work and the interviews were initially conducted separately, but as there was a significant overlap, the data were combined. Throughout this process, to ensure rigour and validity five transcripts and a selection of field notes were also read by a second reviewer. In addition, frequent discussions regarding themes occurred with the project supervisors.

The initial descriptive analysis was followed by an analytical synthesis of the themes, exploring how they related to each other. Consideration was particularly given to how the *a priori* BOTT constructs were experienced in the context of high SED. The analysis also explored how themes out with the BOTT constructs fitted with the wider literature in this area. Transcripts from the ABW, and field notes from the focus group, were iteratively analysed to allow further refinement of the themes, as well as a deeper understanding of the wider complexity and nuance within them. In addition, this allowed feedback of findings to the participants to ensure their voice and experiences were accurately captured and represented.

9.3.4 Participants

9.3.4.1 Participant Observation of community groups

As expected, the participants observed throughout the study varied considerably in individual experience and characteristics. However, each of the four groups attracted slightly different members of the community. The (predominantly) women who attended 3D were almost exclusively from Drumchapel and this group was noticeably multigenerational. In addition, many of the mothers who attended had children with an Additional Support Needs (ASN) diagnosis, which was often a motivation for attending the group and needing support. There was a high burden of mental illness in the women who attended, with a large group of women who were, or had been, significantly socially isolated.

The MMS attendees as a population had often experienced high amounts of social exclusion and ranged from their early 20s to retirement age. Almost everyone who had attended had mental health issues and other chronic disease, with many also experiencing trauma and violence (childhood or currently). A significant proportion had spent time in prison, many had addiction issues, or were in recovery. There was an almost universally poor experience of statutory, including health, services. This was particularly marked in their experience of mental health and addiction services.

The participants who used the cycle hub were older, and this may be because the sessions observed focused on beginner skills. Due to the older age, most lived with multimorbidity, and pain secondary to arthritis was common. Attendees at the cycle hub experienced the greatest direct benefit to their physical health, as opposed to MMS and 3D where reports of mental health improvement were more common. Most attendees were women (of note more males attended the longer guided rides).

The Growchapel cohort was much smaller due to the project just starting. The plot holders tended to be middle aged, or older, and all of those spoken to had chronic diseases. They had only just started using their plots but many of them already reported a sense of increased wellbeing, and physical benefits from being in the garden.

Key characteristics (sex, age range, number of chronic conditions) for the interviewees, and those who participated in the focus groups are presented in Table 9.3 and for the ABWs in Tables 9.4 and 9.5.

Table 9-3 Table presenting gender, age, and number of chronic conditions for the interviewees (Those in bold also participated in the focus group)

Interviewee	Gender	Age Range	Number Chronic Conditions (self-reported)
1	Male	60-70	4
2	Male	60-70	4
3	**Female**	**60-70**	**3**
4	**Male**	**60-70**	**3**
5	Male	50-60	2
6	Male	60 -70	3
7	Female	60-70	3
8	Female	50-60	4
9	Female	50-60	4
10	Female	40-50	4
11	Female	50-60	5
12	Male	70-80	4
13	Female	40-50	2
14	Male	60-70	3
15	Female	80 -90	3
16	**Male**	**70-80**	**2**
17	**Male**	**70-80**	**4**
18	Male	40-50	5
19	Female	50-60	6
20	Male	60-70	6
21	Female	60-70	8
22	Female	70-80	5
23	Female	60-70	4
24	Male	60-70	5
25	Male	50-60	4

Table 9-4 Table demonstrating age, gender, and number of long-term conditions for Asset Based Workshop 1

Attendee	Gender	Age Range	Number Chronic Conditions (self-reported)
1	Male	36	2
2	Male	39	3
3	Male	36	2
4	Male	50	4

Table 9-5 Table demonstrating age, gender, and number of long-term conditions for Asset Based Workshop 2

Attendee	Gender	Age Range	Number Chronic Conditions (self-reported)
1	Female	42	2
2	Female	49	5
3	Female	37	2
4	Female	50	5
5	Female	51	4

9.4 Rationale for presentation of Results

The qualitative work comprised 142 hours participant observation, 25 in-depth interviews, two participatory workshops and one focus group. All the work was conducted in one community, Drumchapel. Collectively they explored capacity to manage multimorbidity in the context of high SED and the individual (micro) and community (meso) factors that influence it. As expected, these methods generated a large amount of rich data. To ensure important themes were not missed an abductive, rather than purely deductive, approach was taken to analysis. Rather than deductively apply BOTT subconstructs to the data, a focus on individual and community factors that might influence capacity provided an initial analytic structure; additional themes were developed to reflect the data generated. This allowed the participant voice to build a rich picture of the lived experience of managing multimorbidity in this context.

How best to present these results to demonstrate the richness of the data set, while ensuring key findings, and their relation to BOTT, were clearly highlighted was discussed repeatedly with project supervisors. Given the initial aim of this work, the decision was made to structure presentation focusing on each of the two initial research questions. In summary:

- Chapter 10 presents the individual capacity factors that emerged from the data, before applying them to BOTT and discussing relevant wider literature

- Chapter 11 presents the findings regarding shared community experiences, and how these influenced capacity to self-manage multimorbidity. It discusses the creation of a new construct, “community capacity” to capture this, and situates these findings within the wider literature.

9.5 Covid and the impact on results

As would be expected the experience and impact of covid was a common theme. It also added an uncertainty to how participants described their experience with healthcare as they were unsure how things would look in the future. Although most people did not appreciate remote consulting, there was an acceptance of its initial necessity. There was some perceived benefit in some cases (e.g., a short prescription query) but for most the switch to phones had been perceived as negative. There was a high value put on the extra things you experienced from a face-to-face consultation.

> I would rather it's not [a telephone consultation]. I prefer face-to-face because…and I don't know if goes back to the type of work I do, certainly with online stuff, I don't think you can read the room as good as other.
>
> Interviewee 5 (Male, 59)

For a significant minority the changes from the pandemic had been very negative, this particularly seemed to be the case for people who had ongoing appointments with secondary care that were cancelled, rearranged or over the phone with people they did not know. There was a very real sense of abandonment.

> I used to go there every three months, and I have a key worker, but I've not seen her in a year. My psychiatrist will phone and find out how I am, and I don't like that.
>
> Interviewee 21 (Female, 64)

For most participants there was satisfaction with the primary care services during the height of the pandemic, but as data collection proceeded there was a very real frustration that GP surgeries were seen as being shut. This was exacerbated by stories in the media and their own experience of being in the surgery (to pick up a prescription or make an appointment) and seeing empty waiting rooms. Even worse was the significant frustration and confusion post covid of how to access a GP. There was widespread distrust of systems using receptionists to signpost, and large degrees of frustration at the increased work needed to try to navigate healthcare and of inflexible systems.

> ..when they say, go and phone a doctor, and you phone a doctor, and then you're getting brushed away. Because I phoned my doctor last week, because I took a urine infection. And they took my thingy, I had to renew my asthma inhaler. And the wee lassie phoned me back, and she turned round and told me a urine infection or discharge, is no longer a doctor situation, I need to go to a chemist, to

> put under minor ailments. Well, I don’t know what that is.. I’ve still not been at the chemist yet, I’m going this afternoon, my daughter is taking me down this afternoon.
>
> Interviewee 23 [five days later, due to lack of transport until then] (Female, 63)

It is important to note that many of the interviewees referenced their pre-covid experience. While the work started to demonstrate some of the post covid frustrations with the health service the long-term implications of increased digital consulting and long waiting lists remain unclear. This should be considered in the interpretation of results.

9.6 Conclusion

This chapter has summarised the rationale for the presentation of the qualitative results, as well as how the data was collected. It has also described in detail the community of Drumchapel, where the fieldwork was conducted. The next chapter will present the results by focusing on the themes relating to individual capacity.

Chapter 10 Results: Individual Capacity

10.1 Introduction

10.1.1 Aim

This chapter aims to present the themes around individual capacity factors, exploring how they relate to Burden of Treatment Theory (BOTT) constructs, and situate these findings within the wider literature.

10.1.2 Rationale

This thesis sought to understand the potential applicability of BOTT constructs in the context of multimorbidity and high SED. It aimed to understand the under-researched construct of capacity. Given previous evidence, BOTT constructs were expected to be important in managing multimorbidity in the context of high SED. However, what was not clear was exactly which constructs were particularly important and why; this led to the construction of the first qualitative research question.

- What are the key factors that impact capacity to self-manage in patients with multimorbidity living in areas of high socio-economic deprivation?

This chapter seeks to focus on answering this question by presenting the individual level themes that emerged from the qualitative data analysis.

As the PhD is underpinned by BOTT; the topic guide was based on BOTT, and the analyst was aware of BOTT constructs, it would be expected to influence the analysis. However, due to the paucity of work on capacity, important new themes were anticipated. Furthermore, the topic guide intentionally explored the wider lived experience of multimorbidity in the context of SED. Therefore, a broad inductive approach was taken to understand, in-depth, the lived experience, and wider individual and community factors that influenced capacity to manage multimorbidity. The BOTT framework was then used to explore how these themes related to the existing constructs. This chapter will present these results.

Although this work was interested in the under-researched construct of capacity, it sought to explore BOTT's applicability for people living with multimorbidity in a SED community. Treatment burden is an important component of BOTT, and its impact was clear throughout the analysis. Consequently, this chapter presents the themes from the data that related to individual capacity factors as well as the impact of patient work.

The chapter will demonstrate that BOTT is broadly applicable in the context of multimorbidity and high SED. However, there were some themes (biography and being grounded) that were important to expression of capacity but which do not fit within current BOTT constructs. In addition, positive aspects of the practitioner-patient relationship were both enabling and could reduce workload. Therefore, this is summarised separately as a theme, "person-centred care" (PCC) describing the components of PCC, as well as how this influenced capacity.

As discussed in the last chapter the data was collected from interviews, participant observations, asset-based workshops (ABWs), and a focus group. Due to a dictaphone malfunction the focus group could not be transcribed, but contemporaneous field notes were taken. Evidence from observation and the focus group is presented as narrative based on field notes. Where direct quotes are given throughout the next two chapters, their source (either ABW or interviewee number) is clearly marked. Of note the names for the ABW participants have been changed.

10.2 Individual Capacity factors

There were multiple salient individual level factors that influenced capacity to manage multimorbidity. These fell into two main groups: 1) underlying resource; and 2) factors influencing whether (and how) that resource was used.

10.2.1 Underlying Resource

The underlying resource participants had access to influenced capacity to manage multimorbidity and are summarised in table 10.1. For housing, finance and transport a lack of resource negatively impacted capacity. Conversely, when there were no issues raised in relation to these areas participants often not did not recognise their importance until directly asked.

Table 10-1 Table summarising the main factors contributing to the Underlying Resources theme.

Theme	Supporting Extracts
Finance: Multimorbidity, and managing it, often caused extra expense. People often did not notice the positive impact of adequate financial resource. A lack of finance, however, had a significant negative impact on capacity. Financial struggles were repeatedly cited as a reason for not attending appointments, or as a barrier to behavioural changes.	"Aye. See if I…even if it was…even if I could get there no bother, and it's a couple of buses, right, it would still be coming back to affordability. And it's…and that's the killer. And it's…there's not really much now I can cut back on now…things, do you know what I mean." Interviewee 4 (Male, 60)
Accessible Local Resource: Local resources in the community, including access to green space, exercise facilities or shops, were important in supporting capacity. Being able to walk, or take a bus, to the GP was particularly important in terms of managing health.	"I think I cancelled my gym membership, and then decided just when we moved here, we were in Area z, just to run around the football pitch. I said, well, I'll use the football pitch there". Interviewee 13 (Female, 48)
Housing: Housing that fit their, and their family's, needs was important, and most of the interviewees perceived their accommodation as suitable. When not the case it had a negative impact on capacity. Some of the participants owned their houses, but most were social housing tenants.	"No, it's a…there was a wet room, a shower, but I got the doors put round, because it's easier for J to help me so he don't get soaked or whatever, so I got them to put doors round it rather than…no, I like doors everything anyway, because I like the wheelchair and that." Interviewee 11 (Female, 54)
Social Networks: The role of social networks was complex; they could be both positive or negative, and in many cases both. What was notable across the whole dataset was the strong and abundant social connections many experienced within the community (expanded in Chapter 12).	"Yes, because my friends have suffered from mental health as well, so I've always been there to support them, so we've always been there for, kind of, each other and we don't put any pressure on each other when we're feeling like that. We just let each other know if we need to talk. They're just at the end of a phone." Interviewee 10 (Female, 45) "No, it's not that, if he wasn't here, she'd be round like a shot to help me, it's just money money…..Probably that way you gie [give] her [participant's daughter] some then it's a fight to get it off her, she moans she's not got any, so you know what I'll give it back, but [she will] just delete me so I've had that." Interviewee 11 (Female, 54)

Isolation: The high reported levels of social cohesion meant isolation was less common, but where isolation was apparent it had a negative impact on both capacity and general wellbeing.	"It's company as well, and I always like…maybe I think I just miss the company now." Interviewee 12 (Male, 72)
Transport: Having a car, or relatives happy to provide transport, had a positive impact on capacity to manage health, particularly in relation to attending appointments. Good access to a local bus route was another way of increasing independence and capacity. Of note there was no direct bus to the local hospital, this was brought up as a significant issue and barrier for many within the community during both ABWs.	Because there's only one bus a day to go to the health centre, because that's in the shopping centre there, as well. So, by the time you leave to go and get the bus, wait for the bus, if it turns up, sometimes you're late for your doctor's appointments. Interviewee 23 (Female, 63)
Access to health care: Geographical location was particularly important for accessing healthcare, with a value on services that could be accessed via participant's own practice. In addition, being able to navigate access to their own practice, particularly during Covid, was important.	"**P2:** Aye, because Drumchapel Health Centre, the podiatry's not there anymore. **Interviewer:** That's a shame. And have you got a car or anything? Or did you need to get…? **P2:** No, no I don't drive. **Interviewer:** So how did you get to Area Y? You had to go to Area Y twice a week, how did you do that? **P2:** I used to get a taxi. And then my two sons, they drive. If they weren't busy, they would take me." Interviewee 2 (Male, 65)

10.2.2 Utilising Resource

The second main group of factors influencing individual capacity to manage multimorbidity were those that influenced whether available resource could be utilised. These are summarised in Table 10.2.

10-2 Table demonstrating the key factors that contributed to the Utilising Resource theme

Theme	**Supporting Extracts**
Illness Burden: The impact of the symptoms and sequelae LTCs had an important impact on quality of life and capacity to manage. This could be ameliorated with medical aids which enhanced underlying capacity, although some resented needing to use them.	"I would love to go out walking a lot more but then the pain in the leg goes. Even when I'm out kneeling in the garden I've got to come up on my good leg and then drag my bad leg up if I'm on my knees. And it's sore, it is painful. My mental health, lockdown's the worst. So, I hardly go out, confined to the house." Interviewee 19 (Female, 56)
Illness/health behaviour stigma: For some participants there was stigma relating to LTCs, especially mental health problems and health behaviours such as smoking and obesity. Women living with obesity particularly expressed feeling judged in a variety of settings, including those designed to promote healthy behaviours which they then avoided.	"And looking in the mirror thinking you're…it takes away that confidence. I think a lot of people – and I know especially a lot of young girls that have put on weight – and they're feeling the same. And they get slagged off by these skinny lassies, you know. And they're like, oh look at you and calling them names. That is terrible, you know." Interviewee 19 (Female, 56)
Fierce Independence: Several interviewees, and participants in the community groups, were fiercely independent; a characteristic they often spoke of with pride. This could have a positive impact on their capacity where it pushed them to keep doing things for themselves. However, there were instances where this also stopped them accepting outside help, even if it could improve their quality of their life.	"And I have to walk with a stick. I can't walk too far. And I have to use inhalers, because I get out of breath, and I get exhausted, going out. But I don't let it keep me in." Interviewee 15 (Female, 80) "I don't…I won't ask for any help. I'm a stubborn thing. And I…the way I see it is the minute I couldn't do it, then I stop, give up. So, I do a bit myself. And if I can't do it, I'll wait until I can." Interviewee 4 (Male, 60)
Biographical integration: LTCs are recognised to disrupt a person's biography: how they see and define themselves (Bury, 1982). As the study progressed it became clear the extent to which people had accepted diagnoses, and managed to integrate those into daily living, had a very significant impact on their capacity to manage their multimorbidity. To integrate a new biography after diagnosis required work, doing this well was important to enable self-care decisions.	"I'm quite happy. To be honest, I don't know. I've been managing it for years, now, and coping with what I've got….And as I say, if something did come up, or I needed advice on it, I could contact my own doctor. But the way things are now for me, I'm quite happy just to carry on the way it's been for a number of years, now. And, unless anything changed, where I had to go and get advice." Interviewee 20 (Male, 67)

Confusion regarding medical conditions: Participant understanding of their LTCs had an important impact on their capacity to self-manage. There was often widespread confusion regarding diagnoses, and their implications. This could be related to never having had a clear explanation from a clinician, conflicting information between clinicians, or from other sources like media. This was important because if potential benefits of lifestyle changes, or monitoring of LTCs, were not understood participants were less likely to consider doing so. Good understanding of their LTC, but also their unique knowledge of how it affected them, and how they responded to management, were often key for people to be able to self-manage well. Where this was in place, self-management strategies had often been embedded in people’s lives. They were confident of being able to manage their multimorbidity and demonstrated agency in their discussions with practitioners.	**Interviewer:** And that’s when they started the inhalers? **R25:** Aye. So, I still cough a lot and stuff if you know what I mean? **Interviewer:** Yeah, yeah, no I do. And did they give you a diagnosis like asthma, or COPD, or…? **R25:** No, I’ve never had a diagnosis or anything, no. **Interviewer:** Okay. And what, do you need to take these inhalers every day? **R25:** Well, I don’t actually take them every day, I just take them when I feel I need them. **Interviewer:** And is that how you’re meant to take them, or just how you’ve worked out what works for you? **R25:** No, I think I’m supposed to take them every day. Interviewee 25 (Male, 57) “Yes, that’s fine. As I say, it’s something that I’ve battled with on and off for about 20-odd years. It comes and goes. I know myself when I’ve been to like…I’ve had CBT, I’ve been to counsellors and stuff like that when I’ve not really felt the need to take medication, but I’d say the past year has been quite tough, so I knew that I needed to go onto medication.” Interviewee 10 (Female, 45)
Supporting others enhances capacity: Many participants were involved in supporting others, even if experiencing illness burden themselves, and while this was work it also enhanced capacity by providing purpose and building esteem. This was particularly evident amongst the peer supporters in the different community groups who highly valued their roles and described increased knowledge and confidence. Having benefited from support in the past being able to support others in similar situations was particularly empowering.	I think just a little bit of normality and obviously I’m not focussing on myself, I’m focussing on the people that I care for. [Discussing value of care job and how it helps them cope] Interviewee 10 (Female, 45)
Being grounded: Many participants described things that gave them purpose, or provided a deeper meaning within their lives, which in turn contributed to their identity. Examples included spending time	“No, the only time I take, I really enjoy things, as I said, is when I take the wee dog out, and I know she's had a really good day. Like, last night, we were coming down, driving down, and she was sitting in the passenger seat looking

walking, hobbies, pets, choirs or local groups, faith groups, opportunities to be creative. Where these things were cultivated and recognised, they created a foundation of “being grounded” that was very important in enhancing capacity to manage not just health care but all aspects of life. For many work, or volunteer roles (including peer mentors), provided important grounding, and were often essential parts of their identity.	out the window, and I went, you’ve had a good day, and you’ve not even slept yet. You know, just talking to her, like that, and hopefully we’ll get a long lie in the morning. Half seven this morning, licking my face, right, I'll get ready, and over to the grass over there. You know, so it's got me into a routine, also, in the mornings. Whereas before, I would just stay in my bed, stay in my bed, maybe get up for an hour, put the computer on.” Interviewee 18 (Male, 47)

10.3 Patient Work

Treatment burden was evident in multiple ways including attending and co-ordinating appointments, self-management, behavioural changes and remembering medications. This section highlights several themes that appear particularly important in this context.

10.3.1 Biographical Work

Almost all the interviewees had longstanding diagnoses, with much of the management work routinised and embedded into daily life. This sometimes may involve complex processes to establish, occasionally requiring trial and error. However, once embedded and part of their routine, the work became an integral part of life:

> It sounds complicated, but I've been doing it that long, now, It's just a way of life, now. It's just, you just get on with it, just keep taking your pills. And it can be a bit of a pain, right enough, when you've got to go and get bloods done, but because I'm working with the NHS, I'm out and about, I can make an appointment and go and get it done. For all the time you're in.
>
> Interviewee 20 (Male,67)

Biography is widely recognised in the medical sociology literature (Bury, 1982, Juliet Corbin and Strauss, 1985, Simon Williams, 2000). Corbin and Stauss's seminal work “Managing Chronic Illness”(Juliet M Corbin and Strauss, 1988), discussed in chapter 3, exploring the work of LTCs from the patient perspective identified biographical work; the work of maintaining identity in the face of LTCs (Juliet Corbin and Strauss, 1985, Juliet M Corbin and Strauss, 1988). Conducted at a similar time Bury's work described LTCs as a biographical disruption (Bury, 1982).

This was seen in the participant experience in this context where LTC diagnosis often required participants to reframe their biography (meaning and identity work) and navigate integrating this new work into their lives. They also may have to work to prioritise the things in their lives that provided meaning, such as time with their family or spending time outdoors. While this required initial work, once LTCs were successfully integrated within people's biography it enhanced their capacity to carry out other work. The initial work could be substantial, and may involve unseen meaning and emotional work, however once done, and work routines established, it was easier to maintain.

However, it is important to note that this experience was nuanced. For some the experience of LTCs was less a disruption but rather an expected insidious part of life. This is seen in the wider literature where the concept of disruption is less relevant as the shift in illness from acute predominantly infective illness to LTCs that can be controlled has become an expected part of aging (Delbane, 2011, Pound et al., 1998, Simon Williams, 2000). However, in addition disruption was also less acute because of the high prevalence of LTCs, even at young ages, across the community. Indeed, one interviewee who worked at a local welfare rights charity described not realising how "sick" people from Drumchapel were until working there and then being posted to other areas. The high prevalence of morbidity had seemed normal to him until then and he mentioned a time a colleague had pointed this out:

> **Interviewee 17:** "I've worked in some places", he says, "but I've never seen a place"…he says, "the minute you come into Drumchapel, and you walk into that shopping centre, you can see, and you can smell the unhealthy atmosphere and see the unhealthy people that I've never seen in any other area." That was his words. He could see and smell it. He says just the unhealthiness of the people in Drumchapel, you know.
>
> **Interviewer:** How did that make you feel?
>
> **Interviewee 17:** It made me feel that maybe I haven't noticed it myself because I'm so used to it, and I've been brought up here. And I'm noticing it more now when I go out and about. When I'm talking about more affluent areas, I don't see…I mean, you walk around Drumchapel now, and you can see people are unwell, physically, and mentally. I'm more aware of it now. I was aware of it because I dealt with it. The amount of mental health that was in Drumchapel is just unbelievable, for a long while, and it's basically caused by bad housing, poor health, poor diet, no work, you know.
>
> Interviewee 17 (Male, 73)

This "normalisation" of ill-health in areas of high SED, which in turn reduces the biographical disruption of an LTC diagnosis, is also seen in the wider literature (Cornwell, 1984, K. Garthwaite and Bambra, 2017, Katherine E. Smith and

Anderson, 2018). Also, it is important to note that biography can be disrupted by things other than LTCs, significant social upheavals are also important disruption (Simon Williams, 2000). In this work the Covid pandemic presented a significant social disruption, many interviewees were still working through the consequences of it.

However, as well as creating initial work (and identity issues if integration did not occur) a biographical disruption (either by diagnosis, or the Covid pandemic) could equally be a catalyst for behaviour change or improved self-management. Where this happened, while participants recognised the benefits of their changes, they also reflected that the "shock" of the disruption was necessary to motivate change.

> I think…and certainly isn't a get out clause for myself or anything, I'm just talking about the general public, perhaps if there was more wider information and discussions surrounding the diabetes, people might take it a wee bit more seriously. But then it probably was there even when I was going through it, but it's something that I probably thought, oh that doesn't affect me, so I don't need to know about it."
>
> Interviewee 5 (Male, 59)

The wider literature also recognises that the shock of a diagnosis may be a motivator for behaviour change (Bluethmann et al., 2015). However, in the literature, those experiencing high SED have been suggested to be less likely to make changes compared to those from more affluent areas (Wang et al., 2022). Certainly, for some of the participants their diagnoses were less of a shock and instead experienced as a normal part of life. In this group the motivation to consider behaviour changes was minimal, especially if they had failed in the past.

10.3.2 The benefit of work and consequence of failure

In addition, for many this routine self-management work was conducted because participants recognised preventative benefits or wished to avoid symptoms having lived with uncontrolled disease. For others, although they would prefer not to take tablets, go to appointments, or adjust to flare ups it was worth it to have their illness under control.

> I’d rather not take them, but I know I need to take them just now and once I can maybe go back to the nurse to get, sort of, my next update type of stuff is maybe they can reduce what I’m on. But if they turn round and say, no you still need to stay where you are, I’ll be fine with that.
>
> Interviewee 5 (Male, 59)

Changing behaviour was an important source of work for many; where this had been positive and sustained it contributed to wellbeing, enhanced capacity, and often lowered illness burden by improving symptom control. Participants also described multiple strategies, beyond treatment work given by the health system, they had developed to manage their illnesses and improve wellbeing. This in turn enhanced capacity to cope. Boehmer et al’s (2016) work on capacity also identified work itself can be important in increasing capacity in the long-term.

However, it is important to note, there was a negative impact for those who had unsuccessfully attempted behaviour change (which in turn reduced capacity). As mentioned in the previous section the effect of failing, and of people dismissing their effort, negatively impacted self-esteem. It created a vicious cycle whereby as nothing was going to change, participants refused to consider health related changes.

> Try and lose weight, but obviously I’ve been big for…God, 40 year maybe, no, it’ll be 35, when I had my daughter, my oldest daughter’s 37, so after I had her, the weight went on. And just never came off. I tried everything, been to weight management, been to there, no, doesn’t help, nothing.
>
> Interviewee 11 (54, Female)

10.3.3 Navigating the system

A final important source of work was trying to navigate a health system that was often described as inconsistent and confusing, with multiple examples of people feeling lost within it. There was widespread confusion regarding referral timescales or the reason for referrals; when others they knew were seen quicker than them it reinforced feelings the system was not working.

> "Aye. Well, it's the same again. It's…I don't go to my GP unless I don't feel well. And so, it was…you see, I mentioned the surgical consultant, he can't say he is not aware of me now, because my GP has been in touch with him, we'd had a sit down and he said he'd get back to me. I've done everything that they've asked of me and…you know something, I don't want to be disrespectful to the NHS but they're…see the six month, nine month and…I waited over a year for a colonoscopy and my sister-in-law got one within two weeks."
>
> Interviewee 4 (Male, 60)

Trying to navigate the system was frustrating work, and even after putting in a lot of work participants still experienced feeling lost. It also contributed to the shared community experience of systems not working discussed in the next chapter. This had negative feedback on capacity, creating apathy about engaging with the health system. The difficulties with navigation increased as the health system emerged from the pandemic.

10.4 Person-Centred Care (PCC)

Throughout the data collection the influence of primary care practitioners on capacity was clear. There were several key aspects of practitioner care that were particularly beneficial. These crossed the themes already discussed; a good practitioner relationship could support the identification, and utilisation, of resource and reduce patient workload. It is therefore presented as a separate theme, where these keys aspects of the patient-practitioner relationship are summarised under PCC.

10.4.1 Patient as Person

Being seen as a person by a practitioner rather than being defined by LTCs was important. Awareness of social context, and willingness to discuss the impact of LTCs on daily life was valued. One interviewee who had moved in the previous few years described feeling "seen" in her old practice:

> back there [old GP surgery] I felt it was personal. They give you that personal touch, because you go in, and this person really is interested in your life.
>
> Interviewee 13 (Female, 48)

However, in her current practice she described the only focus was her diabetes “number”. She felt there will little interest in her, they focused on their job of managing her diabetes number and little else.

> They say [current GP]…you think it’s their job. I don’t know if you see the difference, it’s like it’s my job, I’ll do my job and that’s it.
>
> Interviewee 13 (Female, 48)

The more holistic approach in her last practice led to valuable discussion about diet, important because much dietary advice based on a Western diet was not applicable. She valued the previous Practice Nurse who, wondering if that may be the case, enquired and then worked with her to adapt her diet. She had tried to raise wider issues at her first diabetes review in her new practice but felt dismissed. Unfortunately, her HbA1c had increased, and despite asking, she was not sure what actions may improve it. She reflected that this made her less willing to attend her current practice or ask for advice from them.

This was treated as a theme on its own because where people experienced being seen as a person not just a patient it had a positive influence on, but was not required to have, a strong therapeutic relationship.

10.4.2 Therapeutic Relationship

A strong, trusted relationship, particularly with the primary care team, was highly valued. When present it had a positive influence on engagement in care and was an essential pre-requisite to power sharing. Several things contributed to the establishment of strong therapeutic relationships.

10.4.2.1 Connection and Trust

Participants had to feel a connection to their practitioner, that they “had their back” and were trustworthy. Of note it often took time for this to develop.

> I think it is probably more the comfort thing. You know that you can go, and you can speak to them, and you can ask them questions and things like that, rather than being a bit wary and thinking, no, I am not going to bother, I will just leave it, it will be fine.
>
> Interviewee 9 (Female, 58)

10.4.2.2 Continuity of Care

Seeing the same practitioner, who knew you, your family, and your conditions, was important. People felt they experienced better treatment because their doctor understood how their LTCs flared. It also meant they were more willing to contact and engage the surgery when struggling. Conversely, the experience of unknown doctors, needing to share their history from scratch and having symptoms dismissed made people avoid attending their GP unless they had to.

> And then every time you go down, you're seeing a locum. And then you've got to sit for about half an hour and explain your history 'cause they can't be bothered looking through the computer. Whereas if I see my own doctor, he knows, or she knows what I've been through 'cause they've been dealing with me for the last ten years.
>
> Interviewee 24 (Male, 63)

10.4.2.3 Challenge and enable

Finally, participants expected their GP to challenge and support them to make required changes. Challenge, provided it was delivered in the context of a secure relationship, was enabling. Interviewee 19 discussed how her current doctors were "*chasing me up*" in contrast to her previous doctors, and she valued this. They had brought up her weight and its impact on her LTCs in a non-judgemental way and supported her to decide the best way forward.

> Because they're helping me, when I said to her I know I need to lose weight. She said yes, you have put weight on. She said, what do you want to do? Do you want to go back to weight management, or do you want to do it yourself? And I would rather go back to weight management.
>
> Interviewee 19 (Female, 56)

The importance of a strong therapeutic relationship that enables PCC is particularly important in patients with multimorbidity (Skou et al., 2022). Shim (2010) recognised the value of a strong, accepting practitioner relationship in high SED settings and proposed the concept of Cultural Health Capital (CHC) as a way of understanding how practitioner-patient relationships could reduce, or perpetuate, existing societal inequalities. She defined CHC as the *"cultural skills, verbal and non-verbal competencies, attitudes, behaviours and* *interactional styles"* (Shim, 2010) that can optimise health care relationships and may reduce the impact of stigma (Chang et al., 2016, Dubbin et al., 2013, Shim, 2010). In this high SED setting high quality PCC could ameliorate the influence of wider community factors and this will be discussed in more detail in the concluding chapters.

10.4.3 Sharing Power

Power, and the sharing of power, was important in how enabled participants felt to manage their health.

> No, I suggested it because I'd told the doctor that my normal coping mechanisms, everything that I normally do, weren't working and I knew that I needed to actually take medication.
>
> Interviewee 10 (Female, 45)

While this could involve decision about specific medical treatments, it more often involved participants feeling empowered to focus on social impacts of disease or discuss the symptoms that were most problematic to them rather than just focus on disease parameters (such as BP or HbA1C targets). Where power sharing occurred, participants saw themselves as active participants. This required a strong therapeutic relationship with, at least, their GP, and sometimes other health care teams. People who felt enabled to make health care decisions with their GP also appeared to feel enabled, and interested, in managing their own LTCs.

10.4.3.1 Reasons power sharing did not happen.

While power sharing appears enabling it rarely happened; there were several reasons for this.

<u>Misunderstanding regarding health conditions</u>

Misunderstanding regarding LTCs influenced whether power sharing occurred because of confusion regarding what, if anything, they should be doing in relation to their health. Some participants explained how they had not acted because they had not understood potential implications. For example, interviewee 18, a renal transplant patient, described

> ..they were checking my bloods, etcetera, they said, your sugar levels are high. But again, I didn't understand totally what they were referring to, I just continued and continued. I was maybe having, like, three litres of energy juice.
>
> Interviewee 18 (Male, 47)

He advised this continued over several six-month appointments before he was diagnosed with diabetes. It was not until that point he became aware of the potential impact the high sugar drinks were having and stopped immediately.

Agency within the practitioner relationship

More common was an awareness of not fully understanding their LTC but tackling this was constrained by a lack of agency in the practitioner relationship. Participants described feeling unable to challenge their practitioner, or assert their priorities or concerns, within GP appointments.

> I think it's just down to my naivety, that I don't challenge things, you know, or just accept things, yeah, I'll do that, or I'll try this, or do that."
>
> Interview 18 (Male, 47)

Lack of connection and trust were particularly likely to result in lack of agency within the practitioner relationship. Discussion in the first Asset Based Workshop (ABW) identified the power discrepancy between patients and doctors, with limited options for patients to challenge this.

> **Gordon:** 'Cause right now, it's about the power dynamic is off. And it's about being able to…if you can raise your voice to a doctor and be accused of being aggressive, right? Fair enough, that's a legitimate perspective. But if I as a patient feel totally undermined by you going, pah, and rolling your eyes, right? Where's my outlet?
>
> **Graham**: None, 'cause they're not giving you anything.

> **Gordon:** The outlet of the doctor is asking you to leave and saying to the reception staff to disengage you and send a letter and if necessary 'phone the police. What's your outlet?
>
> Asset Based Workshop 1 (All names changed and anonymised)

Interviewee 22 described being keen to manage her blood pressure and buying a monitor at home. At the practice's request she took multiple readings over a period and handed them into the surgery. The receptionist phoned her to say they were fine, she then brought it up with the nurse who said not to worry, at which point she decided not to push it more.

> Yes, I said to the nurse, I went, but look at that one there and look at that one there. They are above what they should be. High not like you get moderate and then high, they were high. You just give up now. My friends are the same.
>
> Interviewee 22 (Female, 72)

This resulted in significant frustration; the surgery had suggested a monitor for better blood pressure control, yet when she tried to engage, she felt dismissed. Consequently, when the surgery told her to stop taking one of her antihypertensives she was disinclined to do so:

> The nurse said don't take it at all. I won't listen to her to be honest with you. Maybe in a couple of weeks I will take it just to see.
>
> Interviewee 22 (Female, 72)

Lack of Agency within the system

People struggled navigating a complex health system, already, a significant source of work. This created a feeling of powerlessness in the face of a disorganised and inflexible system that was disenabling to shared decision making.

> **R24:** Well, I wasn't expecting anything like that, but he says, oh you've got atrial fibrillation now…or atrial flirration? whatever you call it, and with having heart attacks before and…I'm still waiting to go get seen, right enough. They let me go home and says somebody'll call you. That was on 10th June.

> **Interviewer:** Right. And nobody's called you since then.
>
> **R24:** No, I've been to my doctor twice about it and what they've told me is they know I'm waiting to be seen, I'll be seen in due course, whatever due course means.
>
> Interviewee 24 (Male, 63)

Often a primary care practitioner could support navigation which benefited capacity. However, particularly post Covid participants felt their GPs were also struggling with a broken system.

Being a good patient

Participants experienced societal expectations to be "a good patient". Enhanced by the pandemic, this included recognising how busy their doctors were, and the importance of not bothering them and wasting their time. Participants described the need for significant symptoms to ensure they did not waste the doctor's time. However, this meant that many did not feel they could "waste time" clarifying self-management. This created stress of not being sure they were doing the right thing.

> **R24:** Well, I've got to be careful now 'cause when I'm reading up on this thing it'll say at any time I could take a stroke. Whether I believe that anyway I'm not really sure. But they've given me tablets which I'm not really comfortable with 'cause I feel sick every day. I'm hoping to get seen at cardiology so I can try and…maybe try a different medication, something that doesn't make me feel nausea every single morning.
>
> **Interviewer:** Right. And did you mention that to your GP when you were in seeing him about your COPD?
>
> **R24:** Yeah, they said, oh this is the best one for you. And I went, okay, no bother. Well, I've been…I'm beginning to question, you know, and then I'm going…I really need to have a sit down with them and say, do I really need to take all this medication. But getting appointment's one thing and obviously with COVID and backlogs and people so busy
>
> Interviewer 24 (Male, 63)

It is important to note that these barriers to sharing of power, apart from lack of agency within the system, are at least partially invisible to practitioners meaning that the dynamic and its negative impact on capacity is liable to persist.

10.4.4 Co-ordination of Care

The importance of someone who could co-ordinate care across all their LTCs became more critical later in the study in the aftermath of the pandemic. Participants struggled navigating an increasingly fragmented health system. This was particularly so for older participants who struggled with new technology:

> No, I wouldn't blame the health service hen. I just, I feel like, I mean, when you used to go and see the doctor, you seen the doctor, and then they gave you a pill, or whatever you had to get done, or they took bloods off you, and all that carry-on. I don't blame the health centre, nothing to do with the health centre, this is something to do with the Government itself. I mean, there's too many people out there now telling you, you go online to do this, and you go online to do that. Well, I don't do online, I don't do Facebook, and I don't do that Google, no, not Google, that face to face thing. I'm old-school, my point of view is, I'm saying, if you need a doctor, you phone up a doctor, and then you get a doctor's appointment to go and see a doctor.
>
> Interviewee 23 (Male, 63)

Co-ordination was the overwhelming "missing" theme in the focus group when discussing person-centred care, with each of the participants sharing stories where they felt lost in the system, something that didn't happen before when they could easily see their GP, or wider practice team. The disappearance of professionals who assumed a co-ordinating role was strongly felt when problems didn't fit, or there were several issues to contend with. This loss was felt more keenly because now they struggled to access their "own doctor". Participants expressed hurt and feeling let down by a system that previously felt like it had cared.

10.4.5 Doctor Centred Care?

Finally, there were a subset of participants who did not want to be overly involved in their health care decisions, they trusted doctors and were keen to just do what they said. This group did not question the work they were asked to do. They trusted their doctors to make decisions, doing so was seen as a marker of high-quality care. As many self-management activities (checking blood pressure) were traditionally professional roles, they were happy for that to continue. Critically, for many the interview was the first time they had ever thought about this.

Marie in the first Asset Based Workshop described how after a discharge from a significant hospital admission on opiates started by the hospital team her GP told her

> **Marie:** And she said to me, she says, we're not going down this road, Marie, right. She went, so we'll give you the prescription once. That's it.
>
> Asset Based workshop 2 (Names changed and anonymised)

In keeping with the power sharing theme many of these patients were keen for their doctor to understand and support them for the more social aspects of their health management. They wanted doctors who cared about the symptoms that mattered to them. However, they also respected doctor's training and knowledge, they believed doctors genuinely knew more than they did in these situations, and many felt it was not their place, and did not want, to be making medical decisions. Marie felt in this situation rather than "falling" into taking addictive tablets for a long time her doctor looked out for her by saying no.

This "trust" in the doctor's knowledge was discussed again later in the same workshop where there was a discussion about the dislike for doctors who asked patients what they thought should happen (which is an RCGP criteria for PCC).

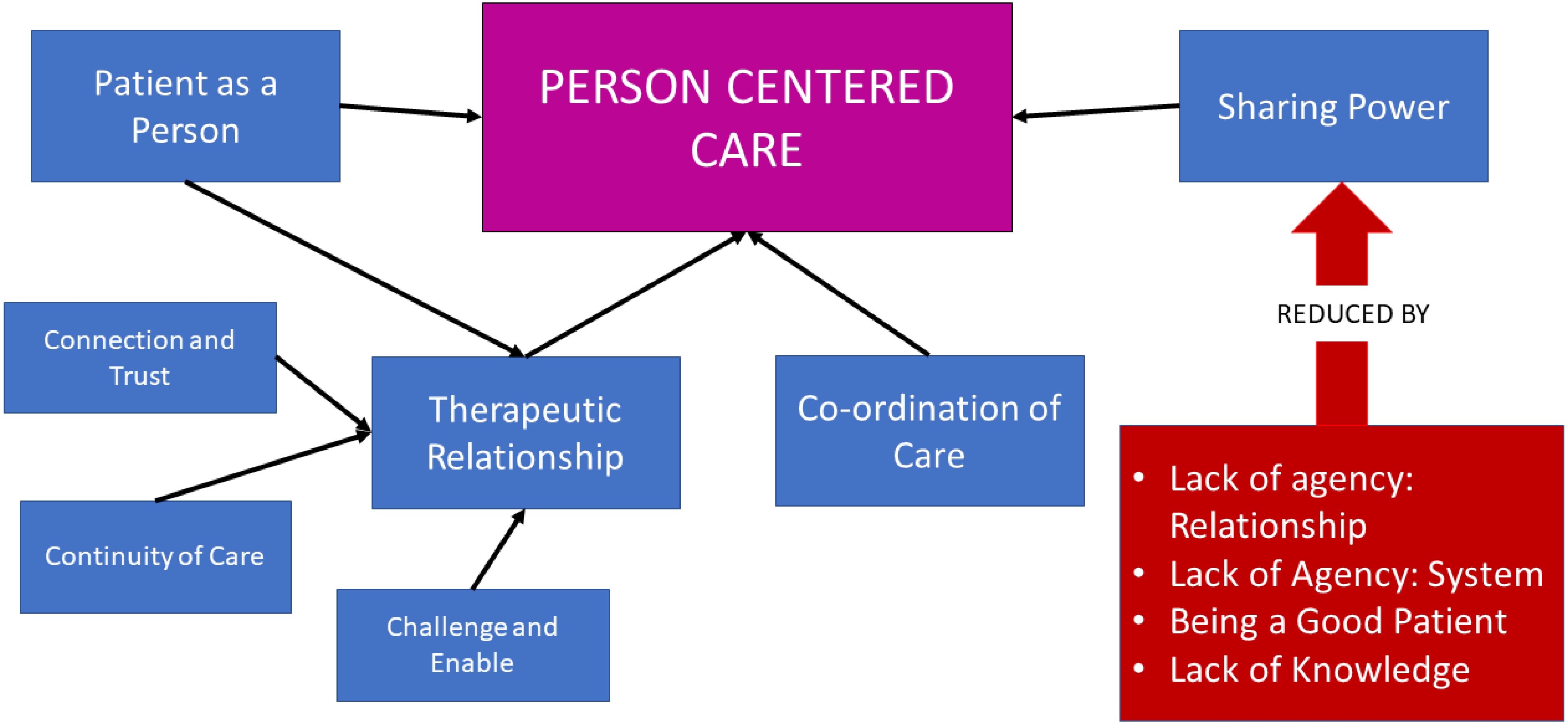
> **Jenny:** So, a few times she said…my doctor said to me, what is it you want me to do? I don't know. You're a GP, you're fully qualified. I'm not. I'm just your patient. I came to you…I've not just picked up the phone and thought, I've had this problem for a day, so I'm going to phone you. It's probably taken me a few weeks to actually make this phone call. Sometimes if it's something else, maybe a few months before I've actually phoned you. And then when I'm coming, you're saying to me, what do you want me to do? I don't know. Do you want antibiotics? Do I need antibiotics? Should be…like, the answer, do you know what I mean, like, do I need antibiotics? Give me them. And just feels as if they don't listen.

Asset Based Workshop 2

It was not clear if this preference for what would be termed doctor-centred care was due to genuine trust, or a lack of self-confidence. This preference is at odds with current recommendations, and training curriculum for GPs in the UK (Royal College of General Practitioners, 2021).

These findings suggest that in a high SED context PCC is important and potentially enabling in a high SED context. In addition, PCC appeared to have a further impact on community factors influencing capacity (discussed in the next chapter). Figure 11.1 summarises how patient as a person, strong therapeutic relationship, sharing power and good care co-ordination interact to contribute to the PCC theme. It also highlights the key factors that stopped power sharing in this context.

Figure 10-1 Figure demonstrating how the different qualities within the person-centred care theme interact, as well as summarising the key factors that reduced power sharing



10.5 Application to Burden of Treatment Theory

After summarising the key data generated regarding individual level factors this section now summarises how these fit with the existing constructs of BOTT. There were several themes that fitted within BOTT but that appear particularly important in a high SED context. For example, illness stigma, not just burden, was important (affecting functional performance), and appeared to chime with community experiences of stigma discussed in more detail in the next chapter. This work also showed that for many there was a particular value in being able to contribute to other’s welfare (enhancing structural resilience).

Although not universal, many of the participants displayed a fierce independence, and a desire to manage things themselves. This had both positive and negative sequalae influencing both the BOTT constructs of functional performance and structural resilience. In addition, confusion about LTCs, or their implications, was common and had an important impact on capacity and influenced several of the BOTT subconstructs.

As discussed, not all work in relation to LTCs is equal. Some of the work people did increased long-term capacity (e.g., by reducing symptom burden, learning new skills, increasing knowledge). This has been seen in other contexts (Kasey R. Boehmer et al., 2016) and this potentially positive influence on capacity should be recognised.

PCC exerted an influence in several ways, primarily through the construct of relationality. A strong therapeutic relationship, and being seen as a person, not just a patient, was empowering and allowed participants to negotiate care focusing on what was important to them. The sharing of power, or lack of it, was very enabling of individual capacity while support to reduce work and navigate the system was particularly beneficial. In addition, the preference for some for a more doctor-centred consulting style may suggest that current PCC models may favour more affluent populations, potentially because they have not included socially vulnerable populations and experience in their conceptualisation (Sturgiss et al., 2022).

Finally, there were some individual themes that did not fit the current BOTT constructs. Both biographical integration and biographical work influenced capacity and treatment burden. In addition, “being grounded” was critical to underlying capacity, and influenced biography but also does not directly apply to current BOTT constructs.

How the themes from the thematic analysis relate to existing BOTT constructs, including the ones that do not fit, is summarised in table 10.3.

Table 10-3 Table demonstrating how the thematic analysis themes regarding individual factors correspond to existing Burden of Treatment Theory Constructs, the themes that appear particularly important in this construct and those that do not fit

Constructs	Thematic Analysis Themes	Supporting Extracts
Thematic Analysis themes that correspond to existing BOTT themes		
Mobilising Capacity		
Agency: Things done to engage with health problems and with others	• Finance	• because I struggle with the bills. I've got council tax bill, and with being in this housing scheme, you pay a separate bill for heating and hot water. That’s £51.72 a month, on top of your electricity bill, as well…… And I find that a struggle. And I told them I didn’t want to pay that, and they told me, they would take my heaters out. Interviewee 21 (Female, 64)
	• Transport	• And you're talking about, it takes me about 15 to 20 minutes to walk, to go and get one bus…..Because there's only one bus a day to go to the health centre, because that’s in the shopping centre there, as well. So, by the time you leave to go and get the bus, wait for the bus, if it turns up, sometimes you're late for your doctor's appointments. Interviewee 23 (Female, 63)
	• Housing	• we stayed in the top flat of the tenements, so I had, like, eight flights of stairs. And it was, I'd go up one flight, wait for five minutes, go up the next. So, it was terrible. Interviewee 18 (Male, 47)
Relationality: Social networks through which agency can be expressed and distributed: can include professional networks	• Social Networks	• I mean, we [family] get on well. We all get on well together. We do lots of things together, you know. Even if I go there, they still take you…they’ve got all these daft things they do on that computer and all that, you know. I mean, we get…meet together regularly, altogether. Believe it or not, they come round here for their dinner…the most we’ve had is 23, Interviewee 16 (Male, 73)
	• Social Isolation	• see you can handle everything when you’re young, but then sometimes you’re sitting here at night now and you think och, you wonder how all these other older ones do it. Interviewee 6 (Male, 60)
Control: What organisations do to determine content, structure, and resources of services.		

Opportunity: Availability of services.	Access local resource	• **Jenny:** what Marie said, because we don't have a bus straight to the hospital from here, so having the physio and the nurses and when you were pregnant, that was a big thing actually, when you were pregnant and most of your appointments were done at the health centre. Asset Based Workshop 2
Expressing Capacity		
Functional Performance: Degree to which people possess cognitive and material capacity to meet demands (including aids)	Illness Burden	• I just couldn't walk because of my hip. I didn't have the walking stick for long enough, just seen it through. My doctor transferred me obviously, get the wheelchair. Interviewee 11 (Female, 54)
Social Capital: How patient's social network can be used for gaining information and resources that help with care	Social Networks	• **Sarah:** you're walking on a path that somebody else has walked on, so they can tell you, right, this is the way it happened for me. It might not happen the same way for everybody but then you've got an idea of the barriers that you're going to come up against or…somebody'll say, right, well this is the barrier you're facing just now. This is what I did. [discussing supporting helping others in the group with benefit applications] Asset Based Workshop 2
Structural Resilience: How patient's network of support can be used to absorb, compensate, and even thrive when things change	Social Networks	• the ones I've told, I'm diabetic, I don't need…because sometimes when you find that they had a birthday party for a resident or somebody, a lot of treats and all these things lying there. So if I pick one and eat, she'll be okay with it, but if you're going for a second, she's like, put that down. Interviewee 13 (Female, 48)
Social Skill: Skills necessary to engage and mobilise cooperation of others, to negotiate controls placed on resources to help with the tasks of care	Navigating the system	• .'cause it's only ten minutes from me. But that was so that I wouldn't need to ask my brother 'cause I know that it is…we're going to be…limited to my…how long I'd be able to do that. [discussing negotiating with team to move hospital can get to with public transport as not sure how much longer can rely on brother to drive] Interviewee 4 (Male, 60)
Treatment Burden		
Understanding, mobilising, monitoring, and adapting work	• Patient work	• Right. I've got a box in the kitchen, and I put a week's supply in it so that I know if I finish a week then I put new ones in. And I've got take them every morning. And plus, the fact that my mum sends me a text – remember your tabs. Interviewee 19 (Female, 56)

	• Navigating the System	• **Jenny:** So I phoned my GP because I had a urine infection. And she says, you can go to your pharmacy. So, I went to the pharmacist. And the pharmacist says, have you got blood in your urine? And I said, aye. She's like that, right… **Marie:** Sent you back. **Jenny:**…you need to go back to the…phone your GP. Asset Based Workshop 2
Thematic Analysis themes that would fit within current constructs but appear particularly important in this context		
Mobilising Capacity		
Relationality: Social networks through which agency can be expressed and distributed: can include professional networks	• Person Centred Care	• But the two doctors that we had…two [girls…two lassies, like, Dr A and Dr B, they're very caring, they're very good. They're…I mean, they take an interest in you, and you're never in five minutes, you know what I mean. They keep you…they look after you. Interviewee 16 (Male, 73) • Because like I say, in the past doctors have ignored and gone, you've got to do something about it yourself or do this, do that, you know. And it's like lectures. Whereas they will sit and talk to you about your health or your mental health and right, what can we do for you? Interviewee 19 (Female, 56)
Expressing Capacity		
Functional Performance: Degree to which people possess cognitive and material capacity to meet demands	• Illness stigma	• when they did my kidney transplant, they left a hell of a scar, which I'm really embarrassed by. And I know that most people would be just, normal people, even I would be doing it, looking at somebody and going, what the hell happened to them, because it's a scar. Automatically, I think that's a negative thing, as they've been stabbed. Interviewee 18 (Male, 47)
	• Fierce Independence	• I don't…I won't ask for any help. I'm a stubborn thing. And I…the way I see it is the minute I couldn't do it, then I stop, give up. So, I do a bit myself. And if I can't do it, I'll wait until I can. Interviewee 4 (Male, 60)
	• Confusion regarding conditions	• That's where I am, and I've not got any appointment, because the last time I talked was last year when I asked for that, what was the number? I said, so what you said, I'm okay, but what's the number, what's the sugar level, what's the number? So, she took time and then she told me some number, 54 or something. So, I just had to google that to see blood

		sugars, but everything you find on Google is kind of American. [trying to understand HbA1c] Interviewee 13 (Female, 48)
Structural Resilience: How patient's network of support can be used to absorb, compensate, and even thrive when things change	• Fierce Independence • Supporting others	• But it's just some days I just feel, no I've got to get out for a wee while. And then of course I get a lecture from him, why did you not wait until I came up. Interviewee 15 (Female, 80) • I think just a little bit of normality and obviously I'm not focussing on myself, I'm focussing on the people that I care for. [Discussing value of care job and how helps cope] Interviewee 10 (Female, 45)
Thematic Analysis themes that do not fit within current BOTT constructs		
Biography: the extent to which people had accepted diagnoses, and managed to integrate those into daily living, had a very significant impact on their capacity to manage their multimorbidity. In addition, this "shock" often was a catalyst for behaviour changes that enhanced capacity. However, integrating biography required work, particularly at the start.		• So maybe if I did something earlier, I would have stopped myself getting the diabetes. But now I've got it, I'm happy to work along with it. Interviewee 5 (Male, 59) • When you're watching certain things, you know, and you go, why did this happen to me. And I mean, I'm not a religious person, but if I was, I'd be doubting God, you know, going, why me? There's people around about that's evil, or bad, whatever you want to call them, and nothing happens to them. Interviewee18 (Male, 47) • When I was diagnosed, I mean, I googled that, maybe information I was given at that time, oh, it was a kick, real kick, because I remember I went…the good thing is, in Area z, where we were living at that time, there was a football pitch, kids would play there. So I used to go with my son and we had a run, so I did a lot of things when I was just told, I was 95 kilograms and I reduced to 82. Interviewee 13 (Female, 48)
Being Grounded: Activities giving purpose, or deeper meaning which contributed to identity. Where cultivated and recognised, they created a foundation of "being grounded" that enhanced capacity to manage not just health but all aspects of life		• They're so connected [wellbeing and choir], it does really help me, because then the going out, first of all, having people to talk to, to do things with, and then obviously it calms you down, because that stress, it really helps, because then you're not stressful. You go out there, you have a laugh, you do stuff, the singing's the best thing anyway. For me I feel it's kind of a medication as well, singing, so it's really, really great. Interviewee 13 (Female, 48)

As the table demonstrates, BOTT is broadly applicable in the context of both multimorbidity and SED, and a useful framework to understand how and why some people manage their illness better than others. Many of the findings chime with the existing BOTT literature. Like work in LMIC settings (Chikumbu et al., 2022, van Pinxteren et al., 2023a) a “lack” of resource is a critical influence in capacity. In addition, while behaviour change, or altering routines, created work, for some this work could enhance capacity. Shorter-term increases in work may be beneficial if they result in long-term enhancement of capacity. (Kasey R. Boehmer et al., 2016).

Findings regarding individual capacity coalesce around the agency and relationality sub-constructs, rather than control and opportunity. This may be because structure and delivery of services was not the focus of this data collection and were less commonly brought up as these were not factors within people’s control. However, there were some examples of how access, and availability of health services, affected capacity. For example, the move of podiatry to a health centre 20 minutes away or that there was no bus from Drumchapel to the nearest A/E. In both these examples this impact was both seen and resented within the wider community; people assumed policy makers either misunderstood their reality or that they did not care.

This analysis also showed two important themes that do not fully sit within BOTT constructs: biography and being grounded.

10.5.1 *Biography and being grounded*

Integrating biography was foundationally important for capacity, and the work involved had an important impact on treatment burden. This coincides with the work of Boehmer et al (2016) who described biography as foundational for capacity to be expressed. In addition, Chikumba et al (2022), in a LMIC setting, described the importance of “coming to terms” with multimorbidity, the importance of meaning in the context of LTCs and the importance of the work involved in this (which they situated within the coherence domain of treatment burden).

Bury (1982) proposed three ways chronic illness can disrupt biography: challenging “taken for granted assumptions”, challenging explanatory frameworks (particularly the question why me?) and the need to mobilise resource required for LTC management (Bury, 1982, Simon Williams, 2000). In terms of managing biographical work Bury identifies two ways: coping (creating meaning and identity in life despite chronic illness symptoms) and strategies (practical work enacted to manage LTCs) (Bury, 1982, Simon Williams, 2000). The biographical meaning work required to reframe biography in the context of the challenge to taken for granted assumptions and explanatory frameworks is partially covered by the coherence (sense making) subconstruct of TB. However, the subconstruct of coherence focuses primarily on the cognitive process of understanding LTCs and the work required. These findings suggest that the meaning work first identified by Corbin and Strauss to reframe, and maintain, identity in the context of LTCs is important, and can be a burden.

While biographical work could be included in the construct of TB these results suggest the importance of the work of meaning and identity needs to be explicitly emphasised and explored in the context of TB. Strategies (practical) and coping (meaning) work do correspond with existing treatment burden subconstructs but where health care focuses on supporting biography at all, it is almost solely with practical strategies. The resource, support and time required for coping work, that corresponds with the biographical work recognised by Corbin and Stauss, may be harder to quantify. However, these findings demonstrate it may be important to do so because working through meaning and identity in the context of LTCs was critical in the expression of capacity.

Indeed, it is the impact of biographical integration on capacity expression which is not currently considered within BOTT. The participants who struggled the most with integrating biography were those who were particularly young when they were diagnosed, or for whom the diagnosis meant a sudden change in circumstances (e.g., not being able to work). That disruption has a proportionally greater effect for those diagnosed with LTCs at a younger age is recognised in other contexts (Adem Sav et al., 2017, Simon Williams, 2000). These participants were particularly challenged by losing taken for granted assumptions, and often struggled with the “why me” questions:

> Because when it happened, I was a young boy, and I'd never heard…and they put the tubes in my neck to dialyse me, and I felt great coming off the machine, at first….I was ready to go home, and they said, where are you going, I said, I feel fine…I, but I feel better, I'm back to normal, I'm going home. And then they had to explain it to me. Because I'd never heard of anything like that, I was a painter and decorator, you know. But, aye, it was really tough in the early days with the dialysing. Because my son was only about three or four, and when I came off the machine, I'd done night shift in Hospital G for eight hours, three nights a week. And when I came off, I wasn't good to man nor beast. Other people were getting up and going to their jobs, I just, my blood pressure was so low, I was basically just going to the toilet, and back into bed.
>
> Interviewee 18 (Male, 47)

Where the meaning work related to biography was unresolved and ongoing this created an important barrier to moving on and impaired capacity significantly.

While biography influences both the capacity and treatment burden constructs, being grounded exerted its effect primarily through its influence on the expression of capacity. This theme covered activities that kept people "grounded"; activities that had deeper significance and meaning. Their importance was not always explicitly recognised by participants as they were often integrated in daily life. For many work (employed or voluntary) was a grounding activity, others described creative activities, walking or regular protected times with family. These activities supported wellbeing, and when cultivated kept people "grounded", increasing resilience. This in turn enhanced capacity to manage life, not just health.

Helping people recognise, value, and protect these activities (or start to develop them by exploring what matters to them) could be valuable in developing and maintaining capacity. This theme was closely associated with biography; good integration included people integrating, or prioritising, activities in life that were of value to them and gave them meaning.

10.6 Conclusion

This chapter has presented the key findings in relation to individual capacity and demonstrated that many fit well within current BOTT constructs. This suggests it could be a useful theory for examining multimorbidity issues in a high SED context. It has also highlighted how illness stigma (not just burden), fierce independence, supporting others and confusion regarding conditions may be of particular importance in expressing capacity in this context. It has described the importance of patient work in this context, and how wider factors influence this demonstrating that both capacity and treatment burden are important in this context.

In addition, this chapter has described the key attributes in the patient-practitioner relationship that were enabling in this context. Therapeutic relationships were critically important, while power sharing was enabling but rarely happened. Furthermore, the co-ordinating role of General Practice, previously potentially taken for granted, was becoming increasingly important as the health system struggled post lockdown. Some participants also discussed a preference for consultations that would be described as doctor-centred, which may suggest current models of PCC may be less applicable in high SED settings.

Finally, this chapter has demonstrated that the themes related to biography and being grounded are important in the expression of capacity (and in the case of biography they also contribute to treatment burden). While biographical work is contained in current TB constructs (though it may be of value for this to be more explicitly emphasised) the importance of biographical integration on capacity expression does not fit BOTT as it currently stands. These findings have been seen in other work exploring BOTT suggesting it may require extension to incorporate these critical themes when applied in a high SED setting. The next chapter presents the findings of the importance of community experiences and describes a new proposed construct “community capacity”.

Chapter 11 Results: Capacity and Community Factors

11.1 Introduction

11.1.1 Aim

This chapter aims to present the themes around community factors and capacity, exploring how they relate to Burden of Treatment Theory (BOTT) constructs, and situate findings within the wider literature.

11.1.2 Rationale

This chapter focuses on the final research question:

- How do community beliefs and resources enhance, or limit, capacity at an individual level to manage multimorbidity?

Following on from the findings from the previous chapter, which detailed the impact of individual factors, this chapter will describe the importance of several shared community experiences (Being known, Stigma, Physical environment, Antisocial Behaviour, and None of the Systems Working) that influenced individual capacity. These wider community experiences shaped how participants approached and engaged with all statutory services, including health.

The chapter begins by describing these experiences, and their influence, before reflecting on how these themes fit within existing BOTT constructs. As none of these community themes fully apply to existing BOTT constructs, this chapter will build on these findings, and incorporate the wider literature, to propose a new construct: community capacity. It will argue that individual capacity is shaped and constrained by community capacity and that applying BOTT in this context without considering community capacity risks perpetuating inequalities because of the significant unseen impact of these wider place-based factors.

In addition, a further theme generated from the data influenced capacity. Community Group Engagement describes several qualities (authenticity, safe space, peer support and challenge) integral to community groups that were highly effective at engaging participants and supporting behaviour change. This chapter also describes how this theme influenced community and, in turn individual, capacity. It will then conclude by discussing the key strengths and limitations of the qualitative work.

11.2 Shared Community Experiences influencing Capacity

The individual factors described in the previous chapter are influenced by wider community factors, including clustering of factors that impair capacity (e.g., low income, transport, low literacy). However, there were also specific community level factors that shaped how people accessed, experienced, and viewed health systems, which also impacted capacity.

11.2.1 Being Known: Belonging

Participants consistently described “being known” within their community, which fostered an important sense of belonging and a sense of cohesiveness for many. People often lived just doors away from relatives and friends, and even where this was not the case most people experienced strong supportive relationships with their neighbours.

> ..my point of view, everybody knows everybody. Even though you don't know one person, somebody else knows that person, and vice versa. As I said, one of my neighbours, I've known her since I was a child, and she's been a neighbour of me for, oh – a neighbour, literally a neighbour – for about 30 odd years. So, even though, as I said, we're all different people in the community, but the people that know each other, they're always there for each other.
>
> Interviewee 23 (Female, 63)

It was unusual not to “run into” someone when out and about in the community, this sense of being known made Drumchapel feel safe.

> You tend to find, because obviously it is a sort of community and there are only so many shops and things like that, that now that when you do go into the supermarket or go into the chemist or whatever else, people kinda do recognise you. I suppose, myself, in a sense that is nice. It must be nice for people that don’t have family or

> don't know anyone, that they know that when they go down to the shops to collect their prescription or whatever, that there will be someone there that will pass the time of day with them. I can get how they feel. But, yes, it is nice to have people sort of take time out to have a conversation with you.
>
> Interviewee 9 (Female, 58)

This knowledge, and belonging, could be utilised to manage community-based problems. The gardening group experienced recurrent vandalism not long after it launched, and there were discussions about the need for security cameras, or a police presence. Meanwhile, one of the male plot holders, well known within the community, invited in the teenagers congregating at the plot. He showed them round before taking them to the tool shed, removing the padlock, and telling them to just take what they wanted. The boys were shocked, but he replied it was costing a fortune for the plot holders to replace the padlocks every time they broke in, so if that was their plan, he would rather avoid extra expense. After this conversation the vandalising incidents significantly reduced. In the plot holder's discussion with the council, he explained they were just *"curious lads, you put a padlock on something they are going to want to know why"*.

It is important to note that not all the relationships within the community were positive, sometimes people could "know" too much. Indeed, managing cliques and gossip within the community groups was a constant challenge. In addition, the widespread experience of antisocial behaviour (ASB -see below), and lack of action from statutory services, was what strengthened the bonds for at least some of the participants. For many despite the inherent challenges of living in a community with high SED, the community offered high social capital, which was highly valued, and this has been seen in other work done in similar areas (K. Garthwaite and Bambra, 2017, McKenzie, 2015, Katherine E. Smith and Anderson, 2018).

11.2.2 Being known: Shared social stigma

Participants also discussed the stigma of "being known" as being from Drumchapel by wider society. This shared community experience of stigma was almost universally described. People felt wider society thought of Drumchapel only in a negative light, condemning it for high levels of ASB, addiction and "benefit scroungers". This perception was felt to be unfair with the media blamed for perpetuating unfair stories about their community.

> ..people in Drumchapel know people in Drumchapel, but people outside Drumchapel, like, the media, the telly, the newspapers, things like that, when something happens in Drumchapel, oh it's right there in front of you. But I don't read papers, because papers are just, from my point of view, papers are just a waste of paper. But they just throw it right there and then. So, that's why we get a bad character, because it's [people] outside Drumchapel.
>
> Interviewee 23 (Female, 63)

This stigma was shaming and led to a perception of being judged. It was ingrained so deeply, when people shared their stories at the community groups they commonly started with statements like "*I know people say that folk from the Drum are…but I am…*" to pre-empt an expectation of judgement.

This experience and impact of stigma was articulated by different participants, but is also recognised in a high SED context within the existing literature (K. Garthwaite and Bambra, 2017, Kayleigh Garthwaite et al., 2016, McKenzie, 2015, Katherine E. Smith and Anderson, 2018, Stambe and Parsell, 2023). Stigma is defined as *"the co-occurrence of its components-labelling, stereotyping, separation, status loss, and discrimination-… for stigmatization to occur, power must be exercised" (Link and Phelan, 2001)*. It can be experienced at both the individual and structural level (Hatzenbuehler et al., 2013, Peacock et al., 2014).

Stigma was felt deeply by participants, but often not explicitly articulated, rather being something in the background. It was more overtly discussed as the project progressed as participants were directly asked about stigma as it was an emerging theme. Previous experience of perceiving being judged influenced participants willingness to engage with organisations, which in some cases included health. For many their willingness to participate in the community groups, especially MM, was because the group was thought to understand their experience, had members who had lives like them and were committed to not judging.

The growing evidence of the pervasive and persistent impact of stigma suggests that, like SED, stigma should be viewed as a fundamental cause of health inequalities (Hatzenbuehler et al., 2013). A fundamental cause *“influences how people utilise resources that could reduce risk or sequalae of illness and are persistently associated with health inequalities regardless of timescales or locations”* (Hatzenbuehler et al., 2013). Critically, consequences, (e.g., inadequate housing for certain groups) rather than the fundamental cause is often what is addressed. Ultimately, if the fundamental cause is not addressed it will simply assert its effect through other pathways (Hatzenbuehler et al., 2013). While SED and stigma are closely linked, this work, alongside others, demonstrate that stigma and shame have an independent impact on healthcare access, experience and outcomes that may not be immediately, or explicitly, seen (K. Garthwaite and Bambra, 2017, Hatzenbuehler et al., 2013, Peacock et al., 2014, Katherine E. Smith and Anderson, 2018).

While the impact of stigma on inequities in health outcomes is important, and often overlooked, it is also important to remember that the people experiencing it are not helpless actors. Indeed, both individuals and communities use their agency to resist stigma (Hatzenbuehler et al., 2013, Peacock et al., 2014, Katherine E. Smith and Anderson, 2018). Participants in this work resisted this stigma in several ways. They worked hard to highlight the positives within their community. The perceived unfairness of being judged was felt deeply, so people actively highlighted other aspects they felt were not understood or recognised. They described families with strong work ethics who contributed to their community and wider society. They described neighbours and communities that banded together and helped and cared for one another, and they highly valued this, recognising that this is not the norm for many in society. These experiences were often ingrained as part of their identity that served to defend themselves (even if only to themselves and wider family and friends) from the wider judgement of society.

> **Marie:** So, like, a lot of my clients’ families [in affluent areas] will say, and where are you from, Marie? And I’ll say, Drumchapel. And some of them, you actually see their face, like…do you know. And I tell them openly, I'm like, I love Drumchapel. I went, I love where I live. I said, I’ve got great neighbours, I says, I'm still in a tenement close. And they're like, you're what? I'm like that, yeah, some I can…well it’s a top flat, I said, my neighbours are fabulous. I said, we

> have big gatherings round the back, whether it's somebody's birthday and they're having a party and then everybody comes and puts big gazebos up.
>
> Asset Based Workshop 2

These narratives that communities use to portray themselves to resist stigma are also recognised in the wider literature (Cornwell, 1984, K. Garthwaite and Bambra, 2017, McKenzie, 2015, Peacock et al., 2014, Katherine E. Smith and Anderson, 2018). Community and personal identity were often closely integrated. This cohesive picture of Drumchapel frequently referenced by participants, created extrinsic support and encouragement in supporting this identity from within Drumchapel. Family and friendship groups and wider community organisations (including the groups participating in the observation) were key, with people actively choosing to meet stigma by "owning" being part of 'the Drum'.

> **Alistair**: "…to go back to the topic of people pre-empting people's reaction before they describe where they're from, like this I would be from Drumchapel. I think if I'm really honest and based on my experience from talking to a lot of guys in the last few years, there's a pride in coming from quite a dangerous, violent, chaotic scheme. But there's also an embarrassment and a shame and a guilt. And I think that people can own both of those, interchangeably. If I am meeting a group of young people in the town and they know I'm from Drumchapel, then maybe I'm less likely to be assaulted. If I'm meeting a bunch of professionals and they know I'm from Drumchapel, then maybe I'm going to be taken less seriously."
>
> Asset-based workshop 1

This shared narrative being adopted as part of the community identity is also widely recognised in other work (Cornwell, 1984, K. Garthwaite and Bambra, 2017, McKenzie, 2015, Peacock et al., 2014, Katherine E. Smith and Anderson, 2018)

In addition, as well as resisting wider societal narratives, community narratives can enable groups to engage and amplify their voices to tackle problems as a group. Both MM and 3D demonstrated this, where people (often let down by the system) came together to resist as a group. This could be expressed by several mums with children with Additional Support Needs actively supporting (emotionally and practically) a peer to navigate the education or benefit systems. Or the MM group using their collective voice to advocate for improvements in local mental health services. Participating in these community groups built self-esteem and social networks, which had an important impact on capacity.

Another method of resisting stigma was “othering”; blaming a vague description of “others”, not them, who “deserved” the stigma the wider scheme experienced. With high rates of ASB, participants could understand why their community had developed a reputation. However, they then differentiated themselves, and their families, emphasising such behaviour did not represent the entire community. There was a strong desire for this to be understood, and for their experiences to be known and seen as equally valid:

> “No, there’s rogues wherever you go….If you’re not one of them, well, you might know some of them. But then you can blame the environment, for them, you know what I mean? But no, it’s not the worst thing, to grow up in a housing scheme, with the people in it.”
>
> Interviewee 14 (Male, 67)

Similar to other work in this area (Cornwell, 1984, K. Garthwaite and Bambra, 2017, Hatzenbuehler et al., 2013, Peacock et al., 2014, Katherine E. Smith and Anderson, 2018), stigma was then resisted by transferring judgment to these “others”. Often not specific people, they were described as those people perceived to have chosen not to work when they could, expected handouts, or did not look after their property with pride.

> I mean, I don’t like the fact, I’ve got proper illnesses, and that, and I’ve not brought them on myself, most of them. I go down, and I have to wait for a prescription sometimes, and they just walk in, and they get hit with their morphine. I know they just want them in and out, no hassle, so I understand that. But when you’ve been standing 10, 15 minutes, and they just get seen right away, you know. It just gets your blood boiling a wee bit, you know.
>
> Interviewee 18 (Male, 47)

Finally, stigma was resisted by discussing how conditions within Drumchapel were no different to any other housing scheme within Glasgow.

> Not really, because there's other parts of Glasgow are ten times worse, and I'm thinking, people have got bad attitudes towards them as well. But you have to live in these places to know exactly what these places are all about.
>
> Interviewee 23 (Female, 63)

Critically, this meant that judgment regarding Drumchapel was not due to something peculiar about the residents themselves but rather a wider societal demonisation of poor communities. As all these schemes had the same issues and problems, participants situated the stigma within a wider lens of poverty and lack of job opportunities.

11.2.3 Physical environment

The wider physical environment had an impact, which went beyond availability of amenities and services. The rundown, uncared for aspects of the scheme reinforced feelings of stigma; a visible sign of how little they, or their community, mattered.

> Thinking, this is all I'm worth? Well, I don't know but it certainly doesn't…it's just…I mean, if you live in a place that's…that looks good, it makes you feel better.
>
> Interviewee 15 (Female, 80)

Physical environment was not raised spontaneously, but people found they had something to say when asked a direct question. It appeared the physical issues within the area, and lack of investment, had become normalised. However, physical environment influenced people on a subconscious level, with some surprised how strongly they felt when asked to reflect on it.

Another reason it may not have been raised could have been due to the shame of living in an area many spoke of as “a dump”. Therefore, this was often quickly mentioned then dismissed in both the interviews and observations. This widespread view of the scheme as a “dump” meant participants in the Asset Based Workshops admitted scepticism at the start of the process. However, the workshop process revealed assets and positive elements of living in Drumchapel previously not noticed.

> **Jenny:** it's made me think just how lucky we really are. I mean, Drumchapel's not a big, massive place but when you look at this wee map that we've made, it makes you think, well we've actually got a lot of things, do you know, and a lot of people travel outwith to come into our community because we have so much.
>
> Asset Based Workshop 2

11.2.4 The impact of antisocial behaviour (ASB).

On top of stigma there was a further impact from the shared experience of living with high levels of ASB. Often this was indirect, although incidents, and those involved, were widely known within the closeknit community even when not affected. The fallout of high levels of addiction was experienced daily: viewing people inebriated, having paraphernalia such as litter or needles in shared spaces or being aware of wider violence.

For the minority with direct experience of ASB it was very negative and caused significant strain, impacting capacity as they struggled to focus on other things, including health.

> "There's a family right across, and in daft moments, I've felt like going over there and doing stupid things, you know, but I haven't. It's just, that's how I feel, you know, you get them everywhere. I mean, you can knock down, and put new houses up, but you're still going to get dafties in it, you know. And again, I'd sit in my house, and they would maybe – they've not done it for ages, touch wood – but fireworks, they blew my windows open. I came home from a night shift, and my windows were all blown in, my telly was broke, there's still wee bits where the carpet's burnt from the firework. They've maybe threw eggs, or stones, but I couldn't prove it was them."
>
> Interviewee 18 (Male, 47)

11.2.5 None of the systems work

An additional shared community experience of "*none of the systems working*" was reported frequently. This was not just health systems, it was all statutory services and critically it was not just that the system did not work for them, it did not work for anyone they knew.

There was significant shared frustration amid feelings that statutory services were not set up for "the likes of them". The benefits system was particularly troublesome, with only one person throughout the entire study reporting a straightforward experience. For everyone else it was stigmatising, complex and most people required help navigating it. People felt they had to “fight” to have their need for support recognised.

> “Frustrated and angry and I tried…and all that time and when it was my turn to ask for help, nobody would want to give me it. They never, ever at any time told me when the payments started about income tax. By the way, see when it comes to your turn, we’re not going to help you. We’ll just wait and take our nice wages and our nice pension when we retire and sit looking at you as though you’re daft.”
>
> Interviewee 14 (Male, 67)

The process was particularly shaming for those who had always worked but were no longer able to do so through “no fault of their own”. This shame was again often resisted with “othering” whereby even with their own personal experience of being judged, and difficulties with the system, many expressed anger about “others” in their community not working and taking handouts. In contrast they felt they “deserved” support. Furthermore, there were some participants who articulated that they felt people in more affluent areas had a different experience, based on their discussions from friends and colleagues living elsewhere.

> Aye, and I believe there’s other…I don’t know. I just feel that more is done by doctors in these areas for where there’s people with more money, better housing, I just feel they’re listened to more than an area like Drumchapel. That’s how I really feel.
>
> Interview 17 (Male, 73)

11.2.6 Consequence of Shared Community Experiences

Crucially, these shared experiences, especially being known, stigma and none of the systems working, fundamentally altered how people approached statutory systems, including health. The community was felt to be a safe space where people felt known and understood, compared to outside where they had experienced being judged. Unless there was good reason not to, people treated health services as another place where they would be judged, stigmatised and where it was reasonable to suppose the system wouldn’t work for them. This assumption was often validated by experience. This in turn heavily influenced how they engaged with the system, and their capacity and willingness to self-manage.

Extended time spent with those who saw nothing in their environment working illuminated an exhaustion that permeated the community. This is also seen in the literature, where the cumulative experience of stigma means the resource required to combat its continual pervasive effects is eroded over time (Hatzenbuehler et al., 2013, Simon Williams, 2000, Simon J. Williams, 1995). The grinding effect of this persistent and consistent experience and the perceived restriction in options for “people like them” was discussed in depth at both asset-based workshops, and clearly impacted people deeply. They described a system not set up for them, that their communities did not have the skills to navigate, so that even when they tried to push back this was perceived as aggressive. The unfairness of this was visceral for some. It created feelings of helplessness and not being valued, resulting in a cycle of disempowerment negatively impacting capacity. People responded to exhaustion in one of two ways. The first was to get angry and many participants shared stories of “losing it” with receptionists, doctors, or in hospital outpatients.

> **Gordon:** You’re in the doctors, you’re in the hospital, you’re in anywhere and you're right, if something happens, you’re not happy, there’s a way that you can express yourself that’ll mean that people can phone the police and get you taken away. There seems to be in poverty speakin’, or working-class communities, there’s vocabulary that is limited and that limited vocabulary means that you can only communicate to a certain…
>
> **Alistair:** A certain level.
>
> **Gordon:** Aye. And you’re limited in expressing yourself. And if you’re limited in expressing yourself and you’ve also never been shown how to sooth or nurture yourself, then maybe your way of communicating anger and frustration is going to be animated, boisterous and aggressive. But the truth is, that’s not appropriate. And the truth is how do you express yourself in a different way?
>
> Asset Based Workshop 1

There was a widespread recognition that while wrong, and borne out of frustration, it reflected an on-going feeling of not being listened to

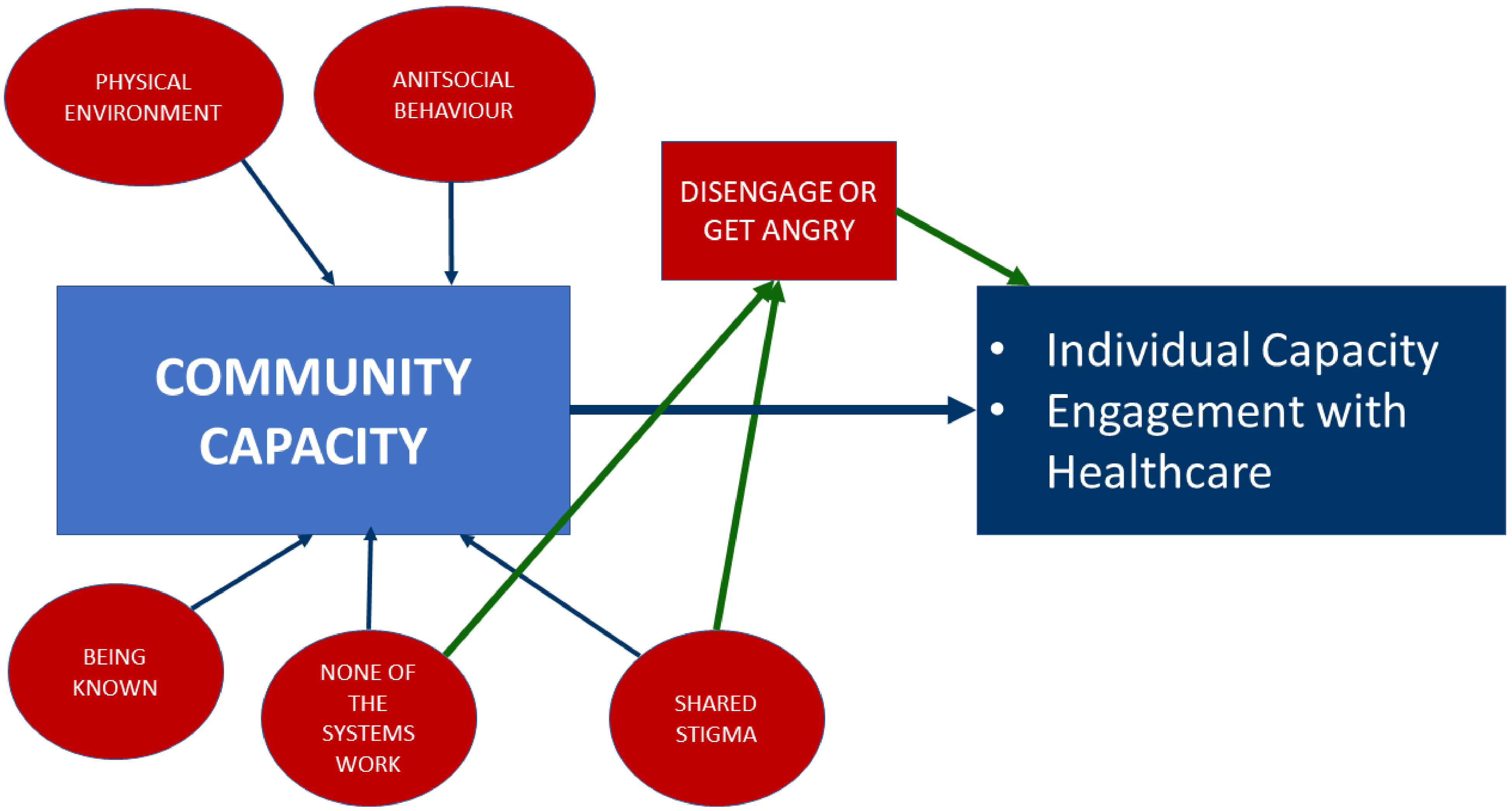
> **Graham:** Sometimes people say you shouldn't shout, you shouldn't say this. It's alright for certain people to say not to shout but if somebody's pressing your buttons, anybody's buttons, you know they're doing it, well sometimes people won't always go to that standard skill of a professional level of speaking, right? So, some people if you get pushed too much you can react in such a way that you can say this and that.
>
> Asset Based Workshop 1

However, the more common response was to simply disengage and accept life as it was. Raised hope caused hurt; believing change was possible was ultimately crushing when nothing changed. Critically this disengagement was likely not visible to practitioners, different participants described how it was "easier" to smile and nod than to let their doctor know they were not going to do something.

These responses, while understandable, created a negative feedback loop: people could be excluded from services (unable to engage in any meaningful shared decision making about their care) or developed a passivity regarding their ability to make changes. This widespread experience shared across the community groups was normalised. When questioned by the researcher it was answered almost invariably with a pitying smile that the researcher just did not understand how the system worked for them.

Figure 12.1 summarises how community capacity influenced capacity and engagement with the health system.

Figure 11-1 Figure demonstrating how the community construct influenced individual capacity.



11.3 Do these Community Experiences fit into BOTT?

These wider community experiences were clearly important, and collectively influenced capacity at the level of the individual. Applying these themes to BOTT as it currently stood demonstrated that none of the themes directly fit with the current constructs. Some of them partially applied to some of the existing constructs and Table 11. 1 demonstrates this for four of the themes (ASB was not felt to fit).

Table 11-1 Table summarising how the shared community experiences fit with current BOTT constructs.

BOTT Constructs	Description	Supporting Extract
Being known		
Mobilising capacity: • Relationality: Social networks through which agency can be expressed and distributed: intensity, size, and complexity of relational networks (which may vary over time). Will include health professionals	• Living in an area where there was an experience and expectation of others helping you out meant that support was experienced beyond immediate social networks. However, while neighbourliness was valued, the supporting extract exemplifies that the actual volume of work, and contribution from the social network of neighbours, was welcomed but often small.	• Aye, there was a lot of garbage out the back, and M down the stair mentioned it, and I carried it all out to the front, you know what I mean, because the binmen were sort of leaving it, you know, wood and stuff. Interviewee 14 (Male, 67)
Expressing capacity • Structural Resilience: How the patient's network of support can be used to absorb, compensate, and even thrive when things change. • Social capital: How the patient's social network can be used for gaining information and resources that help with care	• The experience of being known was highly positive, and valued but there was a limit to how much this could absorb the work of LTCs. However, the wider experience of being known did provide some underlying stability for some, even when things changed. • People often utilised community contacts as ways of gaining and understanding information. These were preferentially utilised to professional sources in many cases.	• I have been in this house 30 years, the last one was 20. Two good houses, good neighbours, I have got fabulous neighbours, so I have all round about me actually. If you needed help, they are all there. Interviewee 22 (Female, 72) • You just get talking to people and you find out, what about this and what about that. And somebody might go to ask me, do you know if there's a…just say a men's group in the area, type of thing. Say, well off the top I can't, no, but I'll find out for you. Just so…I know colleagues and people in the area I could contact to find out. Interviewee 5 (Male, 59)

Stigma		
Mobilising capacity: - Relationality: Social networks through which agency can be expressed and distributed: intensity, size, and complexity of relational networks (which may vary over time). Will include health professionals	- Previous experiences, or stories, of stigma, particularly from health professionals was damaging not just during the immediate experience, but also in being willing to trust practitioners in the future. In these contexts, the trust built in good GP relationships was invaluable.	- I just feel that because you stay in Drumchapel, because you stay in Castlemilk or Easterhouse and that, you're not getting listened to the same, and you're not getting referred to the proper health that you could be, because you're expected to be unhealthy anyway, or you're expected to have a mental health problem, do you know what I mean? Interviewee 17 (Male, 73)
Expressing capacity - Social capital: How the patient's social network can be used for gaining information and resources that help with care	- Participants often relied on their own social networks for support when they became ill, previous experience of stigma and could result in an unwillingness to trust or engage in wider support services.	- **Sarah**: My middle daughter was very challenging when she was younger, especially when she was about 12…well say the age of ten maybe up, and it was really bad. And I spoke to Julie. I went to Julie, and I says, look, this is Louise, blah, blah, blah. And Julie says, right, we'll do Triple P. And I went…but she's ten. No, like…well she was a bit older then. And Julie says, we'll tweak it. We'll tweak it…. **Interviewer:** Can I ask you something, Sarah, if someone else had suggested Triple P, like a health…well you wouldn't have been told by a health visitor but, like, someone at school or the GP, do you think you'd have gone for it? **Sarah:** No. **Interviewer:** So why? Why was it different when Julie offered? **Sarah:** Because we…because there was trust. And I knew that wouldn't go any further than me, Julie, and Louise Asset Based Workshop 2 (All names changed0

None of the Systems working		
Mobilising capacity: • Control over service: What organisations do to determine the content, structure, and resources of services.	• The experience of none of the systems working was compounded by community feeling that decisions regarding service provision were made by people who did not understand their reality. The lack of bus services to the nearest hospital was one such example that was frequently brought up that demonstrated those in charge either did not care or were completely unaware of the community needs. This was widely experienced in other contexts.	• **Gordon:** Sometimes I'll say to the boys that it sort of represents Drumchapel. You pay full price, and you get a dangerously shoddy service and experience. And that's not just against [X] vans where the wheels might fall off or the doors might not shut but it's with the [Housing Association] throwing you up 14 high in a high-rise flat when you're suicidal and your last three suicide attempts were jumping out a window. Asset Based Workshop 1
Expressing capacity • Social capital: How the patient's social network can be used for gaining information and resources that help with care	• The experience of none of the system working created an apathy to believing support was worth pursuing, and an expectation any support would be unavailable even if they tried to access it	• **Gordon:** a mental health support service, on the surface, should be really amazing assets in the community but if they alienate and they anger the individuals that are using them to the point where they disengage, then they're probably doing a little bit more harm than good. Asset Based Workshop 1
Physical Environment		
Mobilising capacity • Agency: Things people do to engage with health problems and with others: impact of physical/psychological/ sensory aspects of disease and disability; material and cognitive resources at their disposal. • Opportunity: Availability of services varies by time and area	• As Physical Environment did relate to physical resource within an area it did partially fit within the agency subconstruct of mobilising capacity. Opportunity also practically covered this theme, in that availability of services included the built environment.	• There were lots of places you could go, clubs and that as well, the Mercat Theatre and everything but everything has just been taken away. I think they are fighting to heat the swimming baths. I know they have wee clubs, but I don't know if they have started up again. Other than that, there is nothing. Interviewee 22 (Female, 72)

Table 11.1 demonstrates that some of these community experiences related in part to current BOTT constructs. However, there were important parts of each community theme that went beyond the existing constructs. In addition, it was the combination of these shared experiences that shaped individual capacity in a way currently not covered by BOTT as it stands. These findings suggest that, in its current form, in a high SED context, BOTT is insufficient as it operates with an assumption that different experiences of systems are purely due to how these systems are resourced and delivered. These results suggest that in the context of high SED there are important place-based factors that influence access to and experience of health systems and shape the decisions people make regarding managing their health.

11.4 Community Capacity

Wider community factors have long been recognised as having an important, pervasive impact on health outcomes beyond individual health risk factors (Foster et al., 2018, Katikireddi et al., 2017). This section will draw on both the existing literature, and the findings from this work, to propose a new construct, community capacity; key community experiences that shape and influence individual capacity.

11.4.1 Internalisation of external community factors

These results appear to demonstrate an internalisation of wider social experience that in turn influences actions at the level of the individual. This fits closely with Bourdieu’s well-established work on habitus (Abel and Frohlich, 2012, Berg et al., 2021, Bourdieu et al., 2010, Høeg et al., 2020, Oncini, 2020, Scott-Arthur et al., 2021, Simon J. Williams, 1995). Habitus is the “*Socially ingrained predispositions or habits*” (Bourdieu et al., 2010, Scott-Arthur et al., 2021) created by a combination of community (often class) experienced “objective conditions” (Bourdieu et al., 2010).

Habitus shapes decisions regarding health, and actions taken to manage it (Batchelor et al., 2023, Scott-Arthur et al., 2021). The dominant narrative within health promotion and policy assumes people are pre-disposed to make healthy choices (Berg et al., 2021, Simon J. Williams, 1995). However, habitus may not predispose individuals towards healthy choices, indeed it may do the opposite (Bourdieu et al., 2010).

In the 3D group mum's night, many mums went to the takeaway together beforehand, and it was seen as an integral part of the "treat" of the evening. The workers advised they had previously attempted to provide and promote healthier food in the evenings, only for it to be strongly resisted. Some of the mum's mentioned this had felt like a judgment on the one thing they did a week "for themselves". The group's purpose was to promote emotional wellbeing not healthy eating, and the 3D workers recognising the takeaway was the one treat many of these women allowed themselves agreed it was not the right place to push a healthy eating agenda. This is also seen in the wider literature where in high SED contexts "unhealthy habits" such as takeaways, or attending the pub, are interweaved with social connection and cohesion, supporting wider wellbeing (Scott-Arthur et al., 2021). This suggests the potential ineffectiveness of highlighting healthy behaviours without understanding, or considering, wider context. It may explain why many health interventions work less well in high SED contexts (Berg et al., 2021); the solutions may not fit the social context they are being applied in.

In addition, habitus restricts what people believe to be possible (Bourdieu et al., 2010), which was seen in Drumchapel where many people accepted, and did not challenge, sub-optimal systems; it was a normal shared experience. This then often resulted in disengagement, because the effort to fight it, or keep fighting, was too demanding. Time and again when asked why they had not complained or challenged the system, participants simply laughed at the ludicrousness of the suggestion. Habitus, and the decisions it influences are often "unconscious practice" (Bourdieu et al., 2010, Simon J. Williams, 1995) and the persistence with which participants described not seeing the point in challenging the wider system suggests this shared experience of systems not working was deeply and subconsciously, ingrained.

Habitus varies by community but, critically some communities have more capital and resource than others and Bourdieu further described *"distinction"*: the process by which choices, actions and beliefs of communities are viewed through the lens of "taste" of the dominant group (Bourdieu et al., 2010, Simon J.

Williams, 1995). This dominant cultural view in turn is considered the norm and seen as desirable. Therefore, other lifestyles, and ways of being in the under-privileged context, are considered deviant, or not worthy (Bourdieu et al., 2010, K. Garthwaite and Bambra, 2017, Scott-Arthur et al., 2021, Katherine E. Smith and Anderson, 2018, Simon J. Williams, 1995). Distinction can result in the imposition of solutions that are logical in the dominant group but do not “fit” in other contexts, such as promoting healthy eating at the mum’s night or the council response to vandalism at the gardening project which was to discuss increasing security.

Critiques of Bourdieu state habitus oversimplifies the complexity of real life and that it does not allow enough of a role for personal agency (Abel and Frohlich, 2012). However, Williams (1995) suggests Bourdieu’s work should be viewed as a bridge between agency and structure, with habitus the context in which agency is expressed. Therefore, habitus could be seen to create a worldview that constrains but does not prevent agency (Simon J. Williams, 1995).

11.4.2 Community Capacity: a new construct

The findings of this work suggest that while BOTT is broadly applicable in this context there is potentially a significant issue if it is applied in high SED communities without also considering the influence of habitus. BOTT assumes that the experience of, and access to, the health system is controlled by the type and delivery of services. However, this work suggests there is an important unseen internalisation of wider community experiences that shape, and in some cases curtail, experience of all services (including health) and the expression of capacity in a high SED setting.

Therefore, this work proposes a new construct, community capacity, that in a high SED context is made up of the shared community experiences of being known, stigma, none of the systems working, physical environment and antisocial behaviour. Simply applying BOTT without considering the wider community context may exacerbate inequalities because it does not acknowledge that in high SED individual capacity is constrained by community capacity. The habitus literature describes a mechanism for how community capacity shapes and constrains individual capacity; it does not prevent individual capacity rather provides the context within which individual capacity is experienced. This allows for the many nuances seen between the different individual participants who shared the same community experiences.

It is important to note that these findings relate to one community in the West of Scotland, and it is likely that similar work carried out in other communities may reveal different, important, shared experiences. The views of the participants that these experiences represented “scheme” life, and the chiming of similar experiences within the wider literature does suggest the five experiences contributing to community capacity in this context have relevance not just in Drumchapel, but in other high SED settings. Furthermore, as the “dominant” cultural experience dictates policy, the habitus distinction literature suggests it is socially vulnerable populations who will be most likely to be disadvantaged by not considering community capacity. Not considering community capacity in high SED contexts, and universally rolling out services designed with the culturally dominant group in mind could perpetuate and widen inequalities. This work therefore proposes a new construct, community capacity, which is the unconscious internalisation of wider shared community experiences that shapes and constrains individual capacity.

As discussed in Chapter 3, previous work conducted in South Africa demonstrated the African concept of “ubuntu”, or the experience of persistent precarity, was important in how people experienced and expressed their capacity (Mbokazi et al., 2023, van Pinxteren et al., 2023a). While the impact of community capacity may vary in different populations it appears that in both the high SED UK context and LMIC settings, wider community factors are critical to capacity to manage multimorbidity (Mbokazi et al., 2023, van Pinxteren et al., 2023a).

11.5 Influencing Community Capacity

As the influence of community capacity on individual capacity was observed during the data collection, the community groups demonstrated certain key qualities that enhanced capacity, at least in part, because of their influence on community capacity.

Participants from the community groups evidenced multiple positive behaviour changes. Cycle hub attendees articulated the difference regular cycles made on their physical health, though for many the positive impact on mental wellbeing was more impactful. For Growchapel plot holders, the structure of having a garden plot, and experience of creating and building something new (the plot but also the wider garden community) was incredibly beneficial. Multiple participants at both 3D and MMS experienced significant improvement in wellbeing, particularly with mental health issues. These two groups were particularly effective at engaging participants who experienced significant social exclusion (including complex trauma, social isolation, offending or addiction issues). There were several important common features that appear critical for these behaviour changes to occur in this context.

11.5.1 Authenticity

For engagement, particularly with more socially vulnerable populations, projects needed to be seen as authentic and relevant to the community. Drumchapel, being known as an area of high SED, often attracted funding with participants accustomed to a rotating door of short-term projects. There was a perception these were started by outsiders who neither understood the community or the people who lived there. The perception was such projects focused on outcomes important to the organisation but not the people themselves. In contrast, three of the projects (3D/MMS/DCH) were viewed by their participants as “rooted” in the community. Both MMS and DCH were started by community members, who were strongly trusted and known within the wider community. Although 3D was not started by the community itself it had been in operation in the community for almost 25 years and was widely respected and valued. Some of the current children supported were the third generation the charity had helped, and it had a strong team of local volunteers who were all from the community. Participants felt that these projects “got” them and their community.

> **Jenny:** They have to be real and cater for the community that they’re serving.
>
> **Interviewer:** And why is that important?
>
> **Sarah:** If you don’t understand the community, you can’t help them.

> **Marie:** If you don't understand the people…if you put things on that people can't afford that's at times that are not suitable, you've got to take all these kind of things into consideration.
>
> Asset Based Workshop 2

This authenticity was important for initial and ongoing engagement especially for those from more marginalised backgrounds where it reinforced the shared community experience of being known and belonging. It also reduced the perceived risk of being judged, in contrast to external organisations.

> **Graham:** Your bullshit detector, knowing that people are not being authentic, knowing that people are being disingenuous, knowing that people don't want to be talking to you. Knowing that people don't really care about listening to what your problems are, knowing that people have already made a judgement about you before you've walked in. Knowing that people have already made their mind up, knowing that people already know what the answer is – oh, here we go, another one that wants put on the waiting list for this and that. [talking about experience of local mental health services]
>
> Asset Based Workshop 1

This need for authenticity for engagement is seen in the habitus distinction literature where activities needing to be seen as *"for the likes of us"* for people to consider getting in involved (Bourdieu et al., 2010, Scott-Arthur et al., 2021).

11.5.2 Creating Safe Accessible Space

Critical to engagement was the ability of these authentic groups to create multiple access points to the service. Criteria for accessing the groups were minimal with many ways to get involved. In addition, those running the groups worked very hard to create safe non-judgemental spaces. This was particularly important for the 3D and MMS group who were dealing with a particularly vulnerable cohort, many of whom had experienced significant trauma and struggled to trust.

For example, the MMS always had a welcomer on the door who took their job to welcome each man, and ensure they felt valued, very seriously. People signed in (for fire regulations) but were also asked to give a percentage (like a battery) of how they felt coming in and going out. It took several attendances to realise a low level, or a persistent level of below 60%, were triggers for volunteers to gently enquire further and offer private space to chat if needed.

A safe space was created and maintained by these groups in several ways. The groups all had clear group rules, which were regularly referred to, strictly adhered to and in the case of MMS and 3D policed by the group members themselves. In addition, workers and volunteers would invest significant time building relationships with newcomers, supporting them to advance to further groups at their own pace. All the groups cultivated an atmosphere of mutual encouragement between members, recognising and celebrating the wins, and empathising when things were difficult. This resulted in ownership by many of the participants in all the groups, with an integration of responsibility to further their groups aims; it was not just the role of the paid workers.

This safe space was fundamental to initial and ongoing engagement, and for MMS and 3D it was the foundation of all the other work they did. It was recognised and highly valued by participants.

> **Marie**: “it was never just about the kids. 3D to me is just a home. It’s everybody. It takes in all walks of life; it takes in everybody. Like, you’re never judged, you’re just part of a big family.
>
> **Jenny**: I was going to say that 3D is, like…
>
> **Marie:** That’s what it’s like. It’s a big, big, massive family.
>
> **Jenny:**…it’s like a family. It’s not like a group. It’s like coming to a family gathering.
>
> **Marie:** Uh-huh. And everybody can speak, and everybody can have their own opinion. And Claire and Shona [leaders] and whoever else will…and they’ll do their best to try and…
>
> **Interviewer:** Hold it?
>
> **Marie:**…keep everything together, do you know, and, like, you could have problems with one person, or you could have problems with one group that you didn’t like and…do you know, you can discuss anything.
>
> Asset Based Workshop 2

As an observer this atmosphere was immediately apparent, although it is hard to easily measure or objectively explain it. In the main, creating these safe spaces was the job of experienced community workers and required significant behind the scenes planning and organising. They recognised it was critical before people would engage in the more complicated interventions and support.

11.5.3 Utilising the Power of the Peer

All the groups used trained volunteers, many of whom had benefited from the group. Growchapel had considerable formal support from other community gardens, and charities. However, informally, the experienced plot holders helped those with less experience, and were often more effective than the formal support. The other organisations all used volunteers that lived in the community; familiar and trusted faces facilitated positive change amongst service users, particularly those previously hard to engage.

> **Sarah:** I was being…you've…you're walking on a path that somebody else has walked on, so they can tell you, right, this is the way it happened for me. It might not happen the same way for everybody but then you've got an idea of the barriers that you're going to come up against or…somebody'll say, right, well this is the barrier you're facing just now. This is what I did. So you're getting lived experiences.
>
> Asset Based Workshop 2

As discussed, the process of supporting others was beneficial for the volunteers, in turn having a positive impact on their capacity. Literature exploring the impact of peer support has demonstrated it may be particularly valuable in high SED contexts, especially where there is flexibility of the nuance the role may require, and time is taken to build trust (Embuldeniya et al., 2013, Sokol and Fisher, 2016).

It is important to note that these peers operated within the context of the safe space and structures the groups had already created. There was significant oversight and support for each of them, important given the potential vulnerability of those they were supporting. The potential negative impacts of peer support seen in the literature are mentor over-involvement because of lack of boundary setting or structure, or increasing the experience of mentee isolation because the mentor does not recognise their social experience (Embuldeniya et al., 2013). Other work has demonstrated that peer support in isolation can have limited impact because of issues developing relationship and time constraints (Christine A Murphy et al., 2008). Therefore, as this work demonstrated, peer support is more effective if conducted within a safe community space, with clear structures and supports for mentees and mentors.

11.5.4 Tension of Safety and Challenge

While creating a safe space was valued, the organisations also sought to create beneficial changes for those using their services. This required balancing safety with challenge and managing the tension between the two. The organisations employed strategies, often evidence-based, that were relevant to their users and would facilitate and support change. They also were open and clear about the ethos and aim of the organisation to new service users from the outset. Yet, they were mindful that change was challenging and emphasised the importance of an individualised approach. The effectiveness of safe spaces, and delivering challenge within that context, is likely at least in part that it negates the impact of wider stigma (Hatzenbuehler et al., 2013, Peacock et al., 2014).

An example of this would be in 3D where one experienced support worker (Julie) was among several staff trained in a new parenting wellbeing course by a national charity. The charity covered training costs with the expectation the resources and materials would be used in 3D, and the workers highly rated the materials. However, due to staff shortages there had been a delay in running the first course and 3D was under pressure to start. In the meantime, Julie had identified several mums she felt would particularly benefit. However, they were more complex, and none had ever taken part in group work before. Therefore, she created a “pre-group” course, demonstrating safe group work and exploring ways to express emotions in a safe way. She called it a “safe space group” (which led to the naming of the previous theme) and talked about how difficult it had been to withstand the pressure from a large national charity to not proceed without it. She was clear on two things. Firstly, she could have run that group earlier with mums who had fewer needs who would get some benefit, but they were not the group she felt needed it the most. Secondly, the time put in to ensure this potential group were able to engage with the material, although more work for her, would result in better outcomes for the mums who needed it most. Challenge could be accepted, and even embraced, by participants, delivering positive outcomes, but required relationship and trust, the pace guided by need, rather than set by a fixed intervention.

Having worked with these ladies for over 20 years she suspected a less experienced worker would have targeted the people easiest to engage. Working this way was a deliberate choice, not always easy with pressure from funders to produce hard outcomes. However, the long-term sustained change she had seen over the years, particularly in those she felt needed the support most, motivated her.

The community groups' supportive networks both enhanced the experience of being known while mediating the negative shared community experiences. Providing a safe space, particularly one where people did not feel judged, was critical in negating shared stigma. Where individuals on their own experienced systems not working the group dynamic built collective agency which supported people to successfully challenge and navigate systems that had previously let them down. Importantly, this was particularly effective for those more marginalised, many of whom felt let down by traditional health or social care services. Therefore, these qualities influenced capacity directly, but also indirectly through their influence on community capacity. It is important to note that these qualities are at odds with many healthcare interventions which tend to be short-term, practitioner-led, inflexible, and set in healthcare settings.

While these groups were clearly assets for those attending, most of the people interviewed were not involved with local community groups. This was an active choice for some, suggesting the benefit of these groups will not be universal. However, some did want to get involved but were not sure how to find out about local groups. These assets may be an under-utilised resource, though it is not clear how best to link people to relevant groups. Furthermore, many attendees described initial resistance to joining the group. Many required a personal recommendation, someone taking them (a friend or support worker) or feeling they had nothing left to lose. This shows just how complex the pathway of engagement can be; fully utilising this resource will require more than signposting.

11.6 Strengths and Limitations

One of the important strengths of this work is the ethnographic approach which employed multiple different data collection methods resulting in a rich data set that allowed exploration of “private stories” (Cornwell, 1984). The considerable time spent in the four groups allowed a depth of relationship and trust to be built; it is unlikely that participants would have been as vulnerable in the two Asset Based Workshops without this trust. A further strength is the focus on the participant voice and experience, and the consideration of both the individual and the community level impact on capacity. The underpinning of this work with BOTT adds rigor and facilitates comparison in different settings. However, the abductive approach also allowed generation of relevant themes out with BOTT as demonstrated within this chapter.

An important limitation is the work was conducted within one community and results must be interpreted within that context. Furthermore, Drumchapel has a predominantly white population, and almost all the participants were of white ethnicity. It would be expected that ethnicity would have an important impact on capacity, particularly in the context of high SED but this work was not able to comment on or explore that. Finally, due to Covid the participant observation was limited to only four groups within the community, which means sections of the community, and community experience, could have been missed. Furthermore, the data was collected during the pandemic, which likely impacted people’s response. Also, many participants discussed their capacity in the context of pre-covid experience. While towards the end of data collection some findings emerged on the post covid experience on capacity (for example the importance of co-ordination) this work must be interpreted in the context of the important and yet unknown consequences of the pandemic.

11.7 Conclusion

This chapter has demonstrated that in a high SED context there are wider community factors that have a significant, often unconscious, influence on community capacity. It has proposed that while BOTT is broadly applicable in this context it does not at present sufficiently consider these wider factors. Building on these findings, and on the wider literature, it has proposed a new construct, community capacity, wider shared community experiences that shapes and constrains individual capacity. It has also discussed how certain community group qualities enhance capacity. It proposes that at least part of this effect is due to their influence on ameliorating community capacity.

As community capacity shapes individual capacity applying BOTT in the context of high SED without consideration of these wider contextual, community factors, risks perpetuating and widening existing health inequalities. Therefore, these last two chapters would suggest that in the context of high SED BOTT requires to be expanded to consider biography, being grounded and community capacity.

Chapter 12 will discuss how the findings of all the work packages relate to and influence each other. It will then build on this work to propose an extension for BOTT in the context of high SED.

Chapter 12 Discussion

12.1 Introduction

12.1.1 Aim

The aim of this chapter is to bring together the results of this thesis highlighting how the key findings from the three work packages inform one another and review the strengths, limitations, and the implications of the work.

12.1.2 Rationale

This PhD presents a multi-method study, where different methodologies were applied to answer the following research questions.

1. For current primary, or community, care multimorbidity interventions:
    a. Do they address self-management, treatment burden, patient capacity or socio-economic deprivation?
    b. What is the experience of participants, and what are the components of the interventions that they value or perceive to be of particular benefit? **Systematic Review (Chapter 6/7)**
2. What is the impact, if any, of individual or community factors on mortality and healthcare utilisation? **Quantitative analysis (Chapter 8)**
3. What are the key factors that impact capacity to self-manage in patients with multimorbidity living in areas of high socio-economic deprivation? **Qualitative analysis (Chapters 9-11)**
4. How do community beliefs and resources enhance, or limit, capacity at an individual level to manage multimorbidity? **Qualitative analysis (Chapters 9-11)**

Together, these questions sought to realise the study’s original aim:

- To explore, and start to quantify the influence of, key factors impacting capacity to self-manage multimorbidity in the context of socioeconomic deprivation.

- To explore how individual and community level factors interact to shape health management decisions.

The systematic review explored the evidence relating to multimorbidity interventions, while the quantitative analysis used BOTT constructs to explore associations between capacity factors and mortality and hospital admission. Finally, the qualitative work explored how individual and community factors interacted to influence capacity, exploring the applicability of BOTT in this context. The results of each work package have been reported in the previous chapters.

This chapter explores how the work package findings inform one another and the implications for future practice, policy, and research. It also builds on the qualitative findings to propose an extension to BOTT which would increase its applicability in the context of multimorbidity and high SED.

12.2 Key findings across the work packages

12.2.1 The importance of Community Capacity

The influence of community, and the importance and need to target community level factors, rather than individual choice, has long been recognised (K. Garthwaite and Bambra, 2017, Reeves et al., 2014, Rogers et al., 2015, Katherine E. Smith and Anderson, 2018). Prior to this work the BOTT construct of capacity recognised the importance of community, but focused on how an individual was able to utilise community resources (Carl R. May et al., 2014).

Here, the relationship between community experiences and capacity was explored. The quantitative analysis demonstrated wider community factors, particularly feelings about walking in the dark, had a significant impact on both mortality and hospital admission. The qualitative work described how shared community experiences in the context of high SED influenced individual capacity and proposed a new BOTT construct: community capacity. Drawing on the Bourdieu literature (Bourdieu et al., 2010) this work proposes that individual capacity is shaped, and in some cases constrained, by community capacity. Therefore, efforts to enhance capacity in a high SED context seem more likely to be effective if they address both individual and community factors.

Despite the extensive evidence of the importance of SED in engagement with interventions and health care services, further evidenced in this work, the systematic review demonstrated social context was only considered in multimorbidity interventions if they targeted a specific population, such as families in rural China (Li et al., 2019) or a low-income neighbourhood in the USA (Edlind et al., 2018). Given the important, often hidden, influence of community capacity, failure to consider wider social factors is problematic and thus interventions will need tailoring for deployment in different communities. Rolling interventions out universally without attention to local contexts, especially in areas of high SED, may reduce engagement and widen inequalities.

Finally, the community groups working in the selected area of high SED had an intuitive understanding of the wider community shared experiences that informed community capacity; by applying this knowledge to how they worked they demonstrated engagement and behaviour change, even in populations experiencing high social exclusion. Health interventions are often practitioner led, short term and inflexible, implemented in health care contexts and rarely adapted to suit different community contexts. Certainly, none of the review articles described co-produced projects or community involvement. While it requires more time and resource to work in this way, the findings from this thesis highlights that not doing so risks not engaging the very populations that need support the most. Therefore, rather than focusing whether we can commit the time and resource required to build relationships, authenticity and safe space we must consider whether we can afford not to (A E MacFarlane, McCallum M, Stewart M, 2023)?

12.2.2 Person-Centred Care: an untapped resource?

The importance of person-centred care (PCC) was highlighted in both the systematic review and the qualitative work. As in the wider literature (Sturgiss et al., 2022), the review highlighted the dominance of the practitioner voice. The qualitative findings showed that good PCC can be transformative and influence individual capacity.

A further reason for PCC being so valued in this context could be because of its impact on ameliorating the impact of community capacity. When participants had experienced stigma and nothing working, any interaction with a practitioner carried a risk. Alternatively, where people felt seen, understood, and unjudged by practitioners this had a powerful positive impact. It shifted health care from being one of the services “that didn’t work” to one that was “for them”. This is seen in the literature where the building of patient cultural health capital (CHC) (the knowledge, skills and resource to manage health and navigate health care effectively) requires empathy and a non-judgemental attitude from practitioners (Chang et al., 2016, Dubbin et al., 2013, Shim, 2010). Being seen as a person, and strong therapeutic relationships could have a transformative impact on participant engagement with healthcare, which in turn could be enabling to self-management.

While rare, true power sharing between participants and health practitioners was often beneficial: people reported engagement in their health care and making decisions in line with their values. It may be that power sharing was particularly positive in this context because the experience of “none of the systems working” created a collective experience of powerlessness. As well as habitus influencing engagement, not recognising it in the patient-practitioner relationship can perpetuate health inequalities through patient-practitioner relationships (Shim, 2010). The reasons for a lack of power sharing seen in these results (patient confusion regarding conditions, lack of agency in the practitioner relationship and the wider system, and the desire to be a good patient) could be due to a lack of recognition by the practitioner of the influence of their habitus.

Some of the participants articulated a preference for care that according to current communication models would be described as “doctor-centred”. The literature demonstrates cultural health capital (e.g., high health literacy, ability to navigate systems), expressed within practitioner-patient interactions, is socially mediated; it is harder for socially vulnerable populations to access or build it (Shim, 2010). This is important because those with high cultural health capital experience more beneficial doctor communication (e.g., more time taken to clarify symptoms or to respond to concerns) (Dubbin et al., 2013, Shim, 2010) and they are often seen as “good patients” by doctors (Shim, 2010). As current PCC models of care have not involved high SED populations in their conceptualisation (Sturgiss et al., 2022), they may have inadvertently been based on the experience of those with pre-existing high cultural health capital. This could be a reason for current PCC models not “fitting” for some in high SED populations, something that has been suggested by GPs working in these areas (Blane et al., 2013, McCallum and MacDonald, 2021).

Continuity of care is also widely recognised as important in the literature, but like the findings in this work, this is particularly the case for vulnerable and disadvantaged populations (Ladds and Greenhalgh, 2023). This may be because continuity of care, or more importantly lack of it, could also influence the experience of “none of the systems working”. This could be particularly negative for those who had until recently felt their GPs were different and that the system did work for them. Being “lost” within the system enhanced the collective feeling of powerlessness, which was often emotionally felt. As well as the traditional forms of relational continuity there is a recognition of the value of “*community continuity*” – practices that know and understand their communities and shape services around those needs (Ladds and Greenhalgh, 2023).

Overall, the importance of PCC across the work packages suggests it may be an untapped resource for improving self-management of multimorbidity in high SED. However, the systematic review found that while initial intervention components aimed to shift care to be more person-centred, this inevitably reverted to usual care, often due to wider structural factors. This impact of wider structural factors (e.g. poor integration between different health team systems, time pressures, targets for referrals or prescribing) impeding PCC is recognised in other work (Browne et al., 2014). Meanwhile, most policy responses to improve PCC focus solely on practitioner training rather than understanding the constrained circumstances that practitioners often work in (Royal College of General Practitioners, 2021). Such circumstances are particularly important in high SED settings where a major lack of resource is already a reality (Fisher, 2021, McConnachie et al., 2023). Quantifying the resource (including protected practitioner time) required to support PCC is critical.

12.2.3 Community-led solutions for community problems

The systematic review found that practitioner views were more commonly sought than those of participants. This practitioner bias is seen in the wider literature (Sturgiss et al., 2022). However, those papers that focused on participant experience were the most insightful in understanding efficacy. Moreover, the views of those who did not benefit from multimorbidity interventions generated critical insights that were, until then, unseen.

The value of actively seeking participant voice is evidenced by the rich data generated when taking an ethnographically informed approach which allowed exploration of private not just public stories (Cornwell, 1984). In keeping with the habitus literature (Bourdieu et al., 2010) the influence of community capacity was often subconscious; using in-depth observational methodologies was critical to explore this. Despite a reduction in health inequalities being a stated aim of both the Scottish and UK governments (Public Health England, 2019, Scottish Government, 2018), proposed solutions and interventions do not always have meaningful community input. Failure to account for differences in habitus coupled with the dominance of the practitioner voice may reduce the engagement in services and interventions, which in turn impacts their efficacy.

While negative shared community experiences were found, significant resilience and strength in the community was also observed. The common experience of “being known” within the wider community was positive. The community groups also enabled change by effectively employing peer supporters. Their success suggests that messages regarding health from professionals, or people not felt to have “walked in their shoes”, may be less effective, particularly when conveyed outside of strong therapeutic relationships. Consulting and co-designing with communities could result in innovative, authentic solutions that could start to mitigate gaps in health outcomes.

12.2.4 Managing Tensions

At times there appeared to be tension in some of the results generated. For example, the meta-ethnography highlighted that intervention efficacy likely required balancing the tensions between structure and flexibility. The quantitative work provided a structure that can be built on to measure capacity, while the qualitative work provided nuance and a richness that cannot be reduced to single data points.

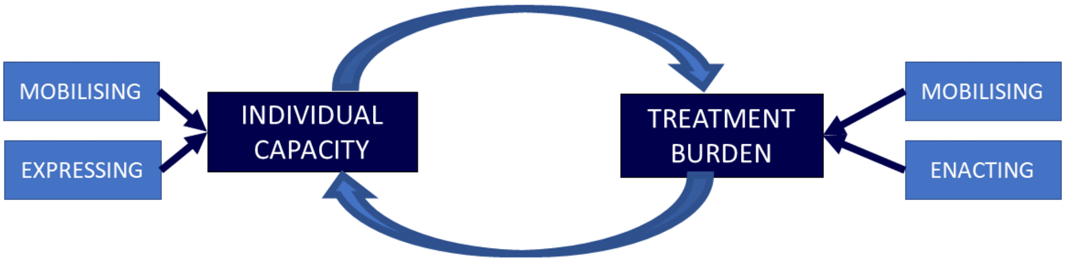
In the qualitative work package managing multimorbidity well created several tensions. Community groups, and PCC, had a positive effect because they managed a tension between safe relationships and challenge. In addition, throughout the work individuals experienced the impact of structural factors but were not without agency. The community capacity construct embraces this: while individual capacity is dependent on multiple individual factors and resources, it is shaped, and constrained, by community capacity. There will be a limit to how individual capacity in areas of high SED can be enhanced without considering the wider factors that influence community capacity.

These different tensions reflect the complexity of managing multimorbidity in the context of high SED, and this thesis emphasises the need for a nuanced approach. Each of the methodologies used here have produced novel, and important, insights that together give a more complete understanding of capacity in the context of multimorbidity and SED. It demonstrates the value of a multi-method approach for complex health problems which require multi-faceted solutions. While the different epistemological and ontological underpinnings of the methods do not allow direct result integration, interpretation in the context of all the results allows for a deeper understanding. Multi-method approaches are therefore crucial in ongoing work to explore capacity in the context of multimorbidity.

12.3 Proposed Extension of Burden of Treatment Theory

This PhD was designed using BOTT as a theoretical framework which informs each of the work packages. Existing BOTT constructs, with the addition of a community capacity model, provided a way to measure capacity at the population level and show how a myriad of capacity factors, both individual and community, are associated with mortality and hospital admission. The findings have demonstrated that BOTT is broadly applicable in a high SED context and is helpful in explaining the persistent inequities in multimorbidity outcomes. However, important capacity factors of biography, being grounded and community capacity have been evidenced in this work that are not fully captured or do not fit within BOTT as it currently stands. Therefore, this work proposes the following extension. Figure 13.1 demonstrates our current understanding of BOTT.

Figure 12-1 Figure summarising current constructs of Burden of Treatment Theory



While BOTT includes some wider social aspects (social capital and structural resilience) within its existing constructs, these factors are relevant only in their application at the individual level. The importance of shared community experience and knowledge are not fully accounted for in BOTT at present.

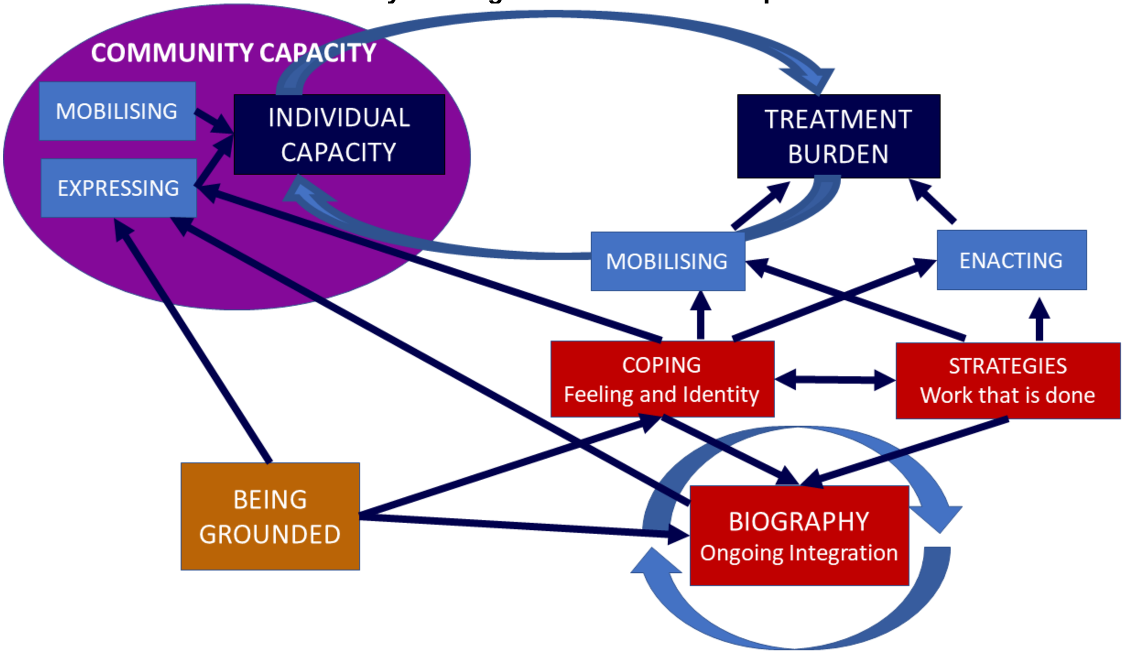
Individual capacity is experienced in the context of the wider community, which in turn affects the experience of many of the individual factors influencing capacity (e.g., access to transport/shops, social networks). However, wider shared community experiences influence the individual experience of capacity. Given the significant influence of these wider factors BOTT may be more applicable/have more utility if community capacity is incorporated, particularly in the context of high SED. While community factors are likely to be important across all communities, these may enhance or bolster capacity, rather than impede it.

As well as wider community factors some individual factors did not completely align with BOTT. Not managing to integrate biography after diagnosis of illness, had a significantly negative impact on capacity. People manage biography in the context of chronic illness in two key ways: coping (creating meaning and identity in life despite LTCs) and strategies (practical changes made to manage sequalae of LTCs) (Bury, 1982, Simon Williams, 2000).

Both coping and strategies represent work (Juliet Corbin and Strauss, 1985), and this work is accounted for within current TB construct. However, the integration of biography and its influence on capacity is not currently clearly articulated. In addition, this work demonstrated the importance of activities that keep you grounded which influences both biography and the expression of capacity.

Figure 12.2 combines the extensions discussed above to present a proposed extended version of BOTT, which would be expected to be particularly applicable in the context of multimorbidity and SED. For clarity, the biographical work is highlighted separately but it's relationship to TB is made clear. Furthermore, the influence of coping work on expressing capacity is also highlighted.

Figure 12-2 Figure proposing an extension to Burden of Treatment Theory that is applicable in the context of multimorbidity and high Socioeconomic deprivation.



12.4 Strengths and limitations

A key strength of this thesis is the multi-method approach, drawing on the strengths of different methodologies. The literature review presents exploratory work, uncovering important gaps in knowledge, and highlighting the importance of qualitative evaluation of multimorbidity interventions. The quantitative analysis presents novel work that is, to my knowledge, the first attempt to explore the impact of a range of capacity factors at a population level, which is grounded in theory. Prior to this work capacity as a concept was under-researched; the qualitative work exploring the concept of both individual and community capacity has provided much needed new insight.

The ethnographically informed approach this thesis took is a particular strength as it allowed the exploration of private stories: making visible what people actually do rather than what they think they do, or are willing to share (Cornwell, 1984). Combining observation with in-depth interviews, the workshops, and the focus group, allowed in-depth understanding of participant experience, as well as access to different sections of the community. The triangulation of these results provides a particularly rich and unique set of data.

All the work-packages were under-pinned by rigorous methodology. The systematic review employed two recognised analytical synthesis methods with the meta-ethnography generating higher order themes grounded in the data. The quantitative analysis used BOTT, used Direct Acyclic Graphs to guide the analysis, providing a clear justification for the variables and methods chosen. In addition, by adjusting for changes in variables over time it demonstrated that as well as these capacity factors changing over time, including adjustment in the analysis alters the association, providing a more accurate reflection of the influence of the variables.

While this work was informed by a well-recognised theory, a flexible analytic approach also allowed the emergence of wider themes. Such themes (community capacity, biographical integration and being grounded) are critical for capacity, and therefore indicate the need for an extension of BOTT. Finally, while the analysis and data collection were all done by the main researcher, throughout the analysis the emerging findings were regularly discussed with project supervisors (one clinician, one non-clinician), both of whom have considerable experience in qualitative methodologies and BOTT. This demonstrates rigour and accountability in the results presented.

Limitations of this work include a lack of diversity; Drumchapel is a predominantly white working-class neighbourhood and recruited participants reflected this. This is also true of the West of Scotland 20-07 cohort which is 98.5% white. Therefore, this thesis predominantly describes the white working-class experience and must be interpreted in this context. The small amount of data from people of colour confirms this was an intersectional factor in terms of stigma, and systems not working, but there was not enough opportunity to explore this in any depth, or to make any clear conclusions.

There are limitations with the West of Scotland cohort, as previously discussed in Chapter 8, especially problems with missing data between and within waves. It also collected information from the 1980s to early 2000s. This is particularly important as this was before the widespread use of smartphones and the explosion in technology and its impact on health cannot be explored and is an important limitation.

A further limitation is that like all ethnographically informed approaches this work cannot claim to fully reflect every person in Drumchapel. In particular, the Covid pandemic reduced the time available for participant observation and to ensure thorough observation only four community groups were observed. This lack of breadth and reach could mean that important elements of the community experience were missed. More time, and the chance to visit more places (especially “crisis” services such as food banks), could have allowed access to deeper experience of those not involved in groups which may have provided valuable information on different barriers to self-management for those with the least resource. In addition, as the results are all from one community, caution may be needed in relation to wider applicability. However, the participants themselves described the findings as part of “scheme life” suggesting they are applicable in other areas experiencing poverty, and likely have broad applicability to Western post industrialised contexts. In terms of comparison within the international literature, all participants had access to the National Health Service; while health care access can be problematic the provision of universal health care meant capacity was not impacted by significant financial impediment to access.

12.4.1 Results in the context of the Covid Pandemic

Previous chapters covered the impact of the Covid pandemic on the methodology and conduct of this work. This section briefly reflects on the impact of the pandemic on the results generated. The pandemic, and the response, had a dramatic impact on life, and health systems, globally. The initial interviews were conducted during the second lock down, the rest as the country was emerging from lockdown restrictions, meaning participants were experiencing significant uncertainty in daily life.

These uncertainties, seen in the data, included increased anxiety, or uncertainty, about how to adapt as restrictions were lifted. The experience of community groups was also often coloured by lockdown experience. In addition, towards the end of the data collection issues with access and problems with basic provision within the NHS became a significant issue. Prior to this there was a large amount of goodwill towards the NHS. However, this slowly started to change, as participants described a growing frustration with the health system, with concerns regarding access and co-ordination that had not existed pre-lockdown.

It is likely these issues have become even more pertinent since data collection finished towards the end of 2022. This thesis was only able to begin to provide preliminary insights into the long-term impact of lockdown, and the current pressure on NHS services. Therefore, much of the interviews reflected people’s capacity in the pre-pandemic context. In addition, the articles identified for the systematic review all dealt with interventions carried out pre-pandemic, and, as discussed, the quantitative data was older. This is important because it is likely the legacy of the pandemic will impact capacity for years to come, and this impact will disproportionately be felt by those experiencing higher levels of SED. The results of this thesis must be interpreted with these uncertainties in mind.

12.4.2 Personal Impact of the Covid pandemic

Throughout the analysis I regularly reflected on the project and the findings as they emerged. This was particularly important through the pandemic; no one experienced lockdown unscathed, and the stress did impact the research process. It was by reflecting I realised the extent of the impact of carrying this work out during a global pandemic and lockdown, with the pressure of supporting my young children. For example, at one stage, worried about time, having finally got ethical permission I had scheduled multiple interviews across two days just as the second lockdown began. Reflection helped me see that the stress I was feeling, particularly regarding adjusting to the whole family trying to work at home together was starting to impact my interviews, and I had started to fall into a “tick box” mentality in the conduct and analysis. I became aware I was approaching them as a task to do, rather than the exploratory process I had hoped to engage in. My project supervisors were invaluable in this time, both in affirming the significant stress the pandemic brought and on reminding me, particularly in the qualitative process, that this work could not be rushed and to give myself time.

To manage this meant slowing down, intentionally making space for reflection when I was in a new context and had calls on my time I had not expected when I designed the project. Furthermore, I had to manage the emotions of making unwanted changes to a project I had spent over a year planning. I had to make time for the emotional work of managing the uncertainty of not knowing what parts of the projects would be feasible, while also managing increased clinical and family pressures. Allowing myself to acknowledge and talk through the added stress of conducting this project through lockdown was critical.

12.5 Implications

The important implications of this work for practice, policy and future research are presented below.

12.5.1 Implications for practice

Capacity and treatment burden are important in the context of multimorbidity, and high SED, and different capacity variables are associated with mortality and hospitalisation. Consideration of patient capacity and treatment burden should become routine parts of LTC reviews in primary care. Explicitly discussing capacity and treatment burden would allow practitioners to better understand that reduced capacity and increased treatment burden challenge optimal self-management for patients. Lifestyle changes represent work but frank discussions about the reality of work may lead to improved outcomes for patients.

Practitioners should consider the impact of biography during LTC consultations, especially during reviews. This could involve explicitly asking about impact of a diagnosis on their usual activities and roles, supporting patients to explore “why me” questions or allowing space to grieve the loss of previous unquestioned assumptions (Bury, 1982). Recognising the foundational impact managing biography has on capacity means this should have parity with other established parts of the LTC review process. Furthermore, practitioners should explore and help patients recognise and prioritise grounding activities as these, often unseen, experiences played a critical role in supporting capacity.

PCC is foundational to government priorities such as Realistic Medicine in Scotland (Scottish Chief Medical Officer, 2015). This work has reiterated the importance of a person-centred approach in primary care, but this requires resourcing, particularly in practitioner time. As the health system finds itself under increasing strain it is critical that PCC principles are not forsaken because of under-resourcing. Given its importance, ensuring delivery in frontline services should be prioritised with the same importance as other markers of quality (e.g., prescribing targets). In high SED contexts, the importance of practitioner response, particularly a non-judgemental approach, in negating the impact of stigma and shame should be highlighted.

Finally, the importance of wider community factors in the patient experience needs to be more explicitly recognised. GPs working in areas of high SED articulate not only an awareness of how wider community factors influence patient’s ability to manage but also a frustration that this is not seen, or resourced, within the wider health system (McCallum and MacDonald, 2021). Resourcing time for practices to understand existing community resource could be valuable. This could be done through the community links workers who should have regular protected time to build links between the practice and the community. The importance of meaningful patient groups within practices should be emphasised, which again could be facilitated by links workers. Practices could use these groups to consult on, and even co-design, practice systems (particularly access and appointment structures).

12.5.2 Implications for Policy

This thesis proposes an extension to BOTT which should increase its applicability in the context of multimorbidity. This could be used to both underpin new service designs, but also evaluate current services. This work has demonstrated that capacity factors are associated with objective and easily measurable outcomes such as mortality and hospitalisation, and SED appears to be an important mediator for these factors. This highlights the importance of taking an equity lens when designing health services. Doing this would allow policy makers to highlight where extra resource may be required to ensure all populations benefit equally from services provided.

Given the importance of PCC, and relational continuity, these should be prioritised in delivery of care to the same or greater extent than timely access. At present much of the active policy and improvement work prioritises access to appointments (Health Improvement Scotland). While it is important to do this simply prioritising access, especially for people with multimorbidity, may come at the expense of continuity and may favour those with the most resource to navigate systems. Policy makers should consider incentivising practices to prioritise continuity within their appointment systems. However, the increase in part-time working in General practice, with increasing demand and a reduced work-force, means the traditional continuity of care between patients with one doctor may be difficult, if not impossible, to achieve (Jeffers and Baker, 2016). One solution may to consider new ways of working that encourage continuity of care, such a micro-team (2-3 doctors working together), though as current evidence is limited (Coombs et al., 2023) any change in working would require rigorous evaluation. Prioritising continuity may mean slightly longer waits for these patients to be seen, and this requires to be communicated to patients.

Policy makers should also seek to identify and reduce the structural barriers to providing high quality PCC, in particular in relation to practitioner time. In a restricted resource health system targeting PCC support to patient populations most likely to benefit, such as those with multimorbidity in areas of high SED or frail elderly, should be considered. This work adds to the growing evidence of the need to urgently reverse the current under-resourcing of practitioners working in high SED areas and of the need to “level-up” general practice (Fisher, 2021).

Health promotion strategies targeting high SED populations must recognise these populations may not be pre-disposed to healthy decisions. Strategies seeking to tackle health inequalities must recognise individual behaviour change models may be limited without targeting community level factors. Furthermore, the need to fund “upstream” drivers of inequality (e.g., housing provision, obesogenic environments) is critical, requiring investment in public health initiatives and co-operative working with sectors other than health.

The significant impact of stigma and shame on health care experience and decision making must also be recognised. Policy discussions and initiatives targeting inequalities can further increase stigma for populations experiencing high SED (Kayleigh Garthwaite et al., 2016). Care should be taken to ensure that communication regarding initiatives to reduce inequalities in health outcomes do not inadvertently increase stigma, and that service designs prioritise dignity and authenticity for service users. This work has demonstrated the resilience, and social capital, within one high SED community and focussing on community strengths and assets, not just deficits, in policy discussions may be an important way to reduce stigma going forward.

This thesis demonstrates the value of capturing the community voice and experience, to illuminate previously unseen barriers and facilitators to self-management in those with multimorbidity. Policy makers should ensure that the patient voice, particularly in high SED contexts, is consulted at every stage of planning, implementation, and evaluation of new and existing health services. This could include harnessing the capital of existing community groups, and potentially using them as vehicles to deliver health interventions to improve health, wellbeing and to reduce inequity. In addition, those commissioning health services should understand, and seek to explore how authenticity and challenge within safe space could be explicitly incorporated, or protected where it exists, within current health care contexts. Consideration should also be given to using peer supporters, particularly in high SED areas. However, this must be adequately resourced, and supporters deployed within a wider structure, with support and time to build relationships.

12.5.3 Future research directions

This work has several important implications for future intervention design. Firstly, it is important that interventions are designed with robust theoretical underpinning and that adequate resource to train and support practitioners is included. Within this, however, flexibility should be built into interventions recognising that understanding where it does not work, and why, is valuable information that can allow intervention adaption and increase efficacy.

For interventions seeking to improve outcomes for multimorbidity the BOTT constructs of capacity (individual and community) and treatment burden should be considered in any intervention design. To improve efficacy, particularly in high SED contexts, underlying capacity and social context should be considered Considering, and resourcing, this could increase engagement and allow all participants to fully participate in the intervention. This will depend on the intervention and context but could include providing transport support if needed, or providing resources in audio versions for people who cannot read. Interventions must also seek to reduce work in the long-term and they need to consider the “work” they require of participants, and, if unavoidable, ensure they provide resource to support them to undertake this work. Finally, the participant voice in the design, implementation and evaluation of interventions is critical; intervention evaluation should include robust qualitative evaluation, at least some of which should review the experience of those who did not benefit or participate.

PCC has an important influence on enhancing capacity, and a critical role in ameliorating community capacity but current PCC models may not be fit for purpose in high SED areas. Therefore, work to explore PCC experience, and preference, in a high SED context, with a heavy focus on patient experience, is critically needed. It also should explore the influence of “being a good patient” in this context. Given the importance of continuity of care, and difficulty delivering it within current health system constraints interventions that explore and evaluate different ways of enhancing continuity should be conducted. Finally, work exploring the system barriers and facilitators to providing PCC for practitioners, particularly what resource is required in terms of practitioner and consultation time, would allow the cost of delivering PCC to be properly quantified, and resourced.

The quantitative analysis demonstrated BOTT could be used to measure capacity at the population level. This work requires to be repeated in other cohorts. Ideally, this should include cohort populations with more social contact information as the only social network information available in this analysis were binary measures regarding whether participants had seen friends and families in the previous four weeks. Exploratory analysis suggested that SED could be a factor moderating outcomes for the Community Capacity factors. Future work to augment the analysis with interaction terms, on the other constructs in this cohort, and other cohort populations, would allow this relationship to be better understood. This could then be built on to create a measure of capacity. This would allow future interventions, and health service designs, to quantify their impact on patient capacity and therefore the cost of not accounting for, and supporting, capacity.

Given its influence on capacity, research to explore what people do (both meaning and practical work) to integrate LTC diagnosis into their biography would be of value. This could inform the design of interventions to support the meaning and practical work required to integrate biography, potentially targeting younger people with LTCs who are likely to experience marked biographical disruption (Adem Sav et al., 2017).

To increase the multimorbidity evidence base for high SED populations, and to ensure potential solutions are relevant and authentic for those community spaces, researchers must ensure they have meaningful community involvement at each stage of the research process. This includes working in partnership with people from areas of high SED to set future research agendas in these communities, and to involve such people in the design and implementation of potential solutions.

PCC, and the qualities demonstrated by community groups (authenticity, safe space, peer support and challenge) appear to ameliorate the influence of low community capacity. Future work is needed to explore whether other factors influence community capacity, and how the findings regarding PCC and community group qualities could be built upon.

12.6 Conclusion

This thesis sought to explore factors that influence capacity to manage multimorbidity in the context of high SED, with a particular focus on the role of wider community factors. While BOTT was recognised as a potentially useful theory in this context, the construct of capacity was under-researched. BOTT constructs mostly applied at the level of the individual and this work was interested to explore the influence of wider community factors.

It has found that despite significant investment in primary care multimorbidity interventions, qualitative work focused on practitioner rather than participant experience and rarely explored the experience of those who did not benefit from such interventions. BOTT constructs, and social context, are rarely considered in current multimorbidity interventions, including the impact of any work the intervention requires. The findings from this PhD suggest this is a critical omission which could result in interventions that contribute to widening rather than narrowing inequalities in outcome.

Future multimorbidity interventions should consider BOTT constructs in their design and ensure their mechanism of change is clearly evidence based while building flexibility into their design. Evaluation, including of where it has not worked, is essential, and the need for ongoing adaptation, particularly in different contexts should be considered part of the research process.

The quantitative analysis demonstrated that BOTT constructs can be used to explore the association of a range of capacity factors on the population level, and that individual and community capacity factors are associated with both mortality and hospitalisation. BOTT constructs are important to consider not just because of participant experience but also because of their association with health outcomes. Future work could build on these findings on create a measure of capacity.

Finally, the qualitative work showed that wider community factors influenced individual capacity. It proposes a new construct, community capacity; the unconscious internalisation of wider shared community experiences that shapes and constrains individual capacity. Important capacity factors of biography, being grounded and community capacity have been evidenced in this work that are not fully captured, or do not fit, within BOTT as it currently stands . Therefore, this PhD proposes an extension to BOTT to be considered in high SED contexts (figure12.2). This extended BOTT could be used to underpin future intervention and health service design in ways that may narrow rather than widen health inequalities.

PCC could be transformative in enhancing individual capacity through strong therapeutic relationships, where patients felt seen. Where power was shared within the patient practitioner relationship it appeared enabling, however, some people articulated consultation preferences that would be defined as more doctor centred. Where they trusted their doctor, and felt they knew them, as their doctor was a medical expert, they often preferred their doctors to make those decisions. Urgent work to fully understand experiences and preferences regarding PCC in high SED settings may suggest adjustments to current PCC models to make them more applicable in these settings.

Community groups demonstrated key qualities (authenticity, safe space, challenge, peer support) that were important to participant engagement and behaviour change. Both these and PCC were important because they could ameliorate the impact of weaknesses in community capacity. Health systems should adapt and learn from the success of the third sector, as well as well as working with people from SED communities in the design and implementation of health services moving forward.

In conclusion, this work has demonstrated both individual and community factors have an important influence on capacity to self-manage multimorbidity in the context of high SED. It also proposes a new construct, community capacity, which shapes individual capacity: applying BOTT in the context of high SED without consideration of wider contextual, community factors, risks perpetuating and widening existing health inequalities.

Health services, and future interventions, should prioritise supporting and optimising person-centred care, work with communities to ensure services are authentic safe spaces and consider utilising peer support for people living with multimorbidity in areas of high socioeconomic deprivation. Finally, an extended BOTT incorporating community capacity, biography and being grounded could be utilised in a high SED context to design health services and interventions for people for people living with multimorbidity. Such services have the potential to improve outcomes and narrow health inequalities in this setting.

Appendix 1: PROSPERO Systematic Review Protocol

A qualitative systematic review of participant experience of primary, or community care, multimorbidity interventions, particularly the extent to which treatment burden, patient capacity, self-management and social context are considered

Citation

Marianne McCallum, Sara Macdonald, Neave Corcoran, Frances Mair, Oscar Ponce, Guy Rughani. A qualitative systematic review of participant experience of primary, or community care, multimorbidity interventions, particularly the extent to which treatment burden, patient capacity, self-management and social context are considered. PROSPERO 2020 CRD42020194094 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020194094

Review question

How, if at all, do current primary or community care interventions for multimorbidity consider treatment burden, capacity, social context and self-management?

What is the experience of participants of current primary, or community care multimorbidity interventions, and what are the components of the interventions that they value or perceive to be of particular benefit?

What are the participants' perspectives of the effectiveness of primary, or community care interventions aimed at multimorbidity?

Searches

Databases: MEDLINE, EMBASE, CINAHL, AMED, and the Cochrane Library.

Restriction: English language.

Searches: 17th- 21st Feb 2020.

Additional search strategy information can be found in the attached PDF document (link provided below).

Types of study to be included

Inclusion:

Qualitative studies carried out in relation to experiences of primary or community care interventions aimed at multimorbidity that have been evaluated within a randomised trial.

Exclusion:

Randomised controlled trials, other experimental studies; before and after studies; cohort studies; cross-sectional studies; observational studies; discussion papers; literature reviews; single case studies/case reports; guidelines; policy statements; and letters.

Condition or domain being studied

Primary or community care interventions targeting multimorbidity management.

Participants/population

Participants in randomised trials of primary or community care interventions targeting multimorbidity management. Inclusion:

Any geographical location; adults (aged over 16); participants in randomised trials of a primary or community care interventions targeting multimorbidity management (two or more long-term conditions).

Exclusion:

Children (aged under 16).

Intervention(s), exposure(s)

Qualitative studies exploring participant experience of primary or community care interventions aimed at patients with multimorbidity that have been evaluated by a randomised trial.

Inclusion:

Interventions:

- Specifically aimed at multimorbidity;

- Community/primary care-based, delivered by primary care staff (definition from the Cochrane review on the effectiveness of primary care multimorbidity interventions (1): "those available to treat all common conditions in all age groups and have an ongoing relationship with their patients");

- Where multimorbidity is confirmed (by the recording of LTCs (long-term conditions)) for each participant;

- Has been, or in the process of being, evaluated by a randomised trial.

Exclusion:

Interventions aimed at patients with comorbid conditions, but only at one condition, and not addressing the full extent of the multimorbidity, e.g., an intervention targeting patients with both diabetes and depression, where the intervention itself only targeted depression would not be included

Interventions targeted at professionals (educational or research) with no clinical element targeting patients with multimorbidity;

Interventions where multimorbidity is assumed (because of age) but not confirmed/recorded, for each participant.

Reference:

1. Smith SM, Wallace E, O'Dowd T, Fortin M. Interventions for improving outcomes in patients with multimorbidity in primary care and community settings. Cochrane Database of Systematic Reviews 2016, Issue 3

Comparator(s)/control

Usual care or none.

Context

Treatment burden and patient capacity are important factors in the experience and management of multimorbidity and influence the ability of patients to self-manage.(1, 2).

Experience and management of multimorbidity is impacted by wider social context; (3) particularly socio-economic deprivation, which leads to increased prevalence (4) and poorer outcomes.(5, 6) Multimorbidity is one of the biggest challenges to global health systems; (7) the numbers of interventions targeting multimorbidity management are growing. The extent to which these interventions have considered the impact of the above factors, if at all, is not known.

References:

1. May CR et al. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. BMC Health Serv Res. 2014;14:281

2. Shippee ND, et al. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. Journ Clin Epi. 2012;65(10):1041-1051.

3. Rogers A et al. Meso level influences on long term condition self-management: stakeholder accounts of commonalities and differences across six European countries. BMC Public Health. 2015;15(1):622.

4. Barnett K et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet. 2012;380(9836):37-43.

5. O’Brien R, et al. The ‘everyday work’of living with multimorbidity in socioeconomically deprived areas of Scotland. Journal of comorbidity. 2014;4:1.

6. Payne R et al. The effect of physical multimorbidity, mental health conditions and socioeconomic deprivation on unplanned admissions to hospital: a retrospective cohort study. Canadian Medical Association Journal. 2013;185(5):E221-E228.

7. The Academy of Medical Sciences. Multimorbidity : a priority for global health research. London: Creative commons; 2019.

Main outcome(s)

The identification of the components from current primary or community care-based interventions for multimorbidity that address self-management, treatment burden, patient capacity and social context.

Patient experience of participating in primary or community care interventions targeting multimorbidity.

Measures of effect

Qualitative experiences.

Additional outcome(s)

None.

Measures of effect

Not applicable.

Data extraction (selection and coding)

Title, abstract and full paper screening will be carried out independently by two researchers aided by Distiller software. Data extraction from the studies selected for inclusion regarding patient experience of primary, or community care interventions targeting multimorbidity will be carried out using a formal data extraction form.

In addition, a data extraction form will be used to determine the extent to which each intervention addresses:

Treatment burden: by analysing if the intervention increases or decreases patient workload, or is workload neutral; then by categorising the nature of any identified work using normalisation process theory; (1)

Patient capacity: by analysing if the intervention enhances or diminishes patient capacity; then by categorising this using Burden of Treatment Theory (2) as a framework;

Self-management: by using the PRISMS (3) taxonomy, a comprehensive descriptive taxonomy of self-management, to identify if self-management is part of the intervention, classifying components where it is;

Social context: components of interventions that explicitly target, or support, patients from communities experiencing SE deprivation will be identified and narratively described.

Data on participant perspectives of interventions will also be extracted.

Discrepancies will be reviewed by a third researcher or member of the research team.

References:

1. http://www.normalizationprocess.org/

2. May CR et al. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. BMC Health Serv Res. 2014;14:281.

3. Pearce G et al. The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility. J Health Serv Res Policy. 2016;21(2):73-82. doi:10.1177/1355819615602725

Risk of bias (quality) assessment

We will use the COREQ tool to assess bias on qualitative studies identified. No

study will be excluded due to poor quality.

Strategy for data synthesis

We plan to carry out a meta-ethnography of the qualitative studies identified to explore the experience of participants in primary or community care interventions targeting multimorbidity, and how, it at all, treatment burden, patient capacity, social context and self-management are considered.

We will seek to identify components of the interventions that patients report of particular benefit.

Analysis of subgroups or subsets

None planned.

Contact details for further information

Marianne McCallum

marianne.mccallum@glasgow.ac.uk

Organisational affiliation of the review

General Practice and Primary Care, Institute of Health and Wellbeing, University of Glasgow

https://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/

Review team members and their organisational affiliations

Dr Marianne McCallum. General Practice and Primary Care, University of Glasgow Dr

Sara Macdonald. General Practice and Primary Care, University of Glasgow

Dr Neave Corcoran. General Practice and Primary Care, University of Glasgow

Professor Frances Mair. General Practice and Primary Care, University of Glasgow

Dr Oscar Ponce. Mayo Clinic (Knowledge and Evaluation Research Unit, Division of Endocrinology, Diabetes, Metabolism and Nutrition, Department of Medicine, Mayo Clinic, Rochester, MN, USA)

Dr Guy Rughani. General Practice and Primary Care, University of Glasgow

Type and method of review

Epidemiologic, Intervention, Service delivery, Synthesis of qualitative studies, Systematic review

Anticipated or actual start date

10 March 2020

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01 October 2021

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State the funder, grant or award number and the date of award

CAF19/05

Conflicts of interest

Language

English

Country

Scotland, United States of America

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Adult; Community Health Services; Cost of Illness; Delivery of Health Care; Disease Management; Healthcare Disparities; Health Status Disparities; Humans; Multimorbidity; Patient Outcome Assessment; Primary Health Care; Qualitative Research; Self-Management; Social Class; Social Environment; Socioeconomic Factors

Date of registration in PROSPERO

11 November 2020

Date of first submission

10 November 2020

Stage of review at time of this submission

Stage	**Started**	**Complete**
Preliminary searches	Yes	No
Piloting of the study selection process	Yes	No
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

11 November 2020

Appendix 2 Systematic Review Search Strategy

Ovid Medline Search Strategy

1. comorbidity/

2. (comorbid$ or co-morbid$).tw.

3. multimorbidity/

4. (multimorbid* or multi morbid* or multiple morbid*).tw.

5. (multidisease* or multi disease or (multiple adj (ill$ or disease? or condition? or syndrom? or disorder?))).tw.

6. or/1-5

7. chronic disease/

8. (chronic$ adj3 (disease?or ill$ or care or condition or disorder$ or health$ or medication$ or syndrom$ or symptom$)).tw.

9. 7 or 8

10. 6 or 9

11. exp Diabetes Mellitus/ or diabet$.tw.

12. exp Hypertension/ or (hypertens$ or "high blood pressure?").tw.

13. exp heart diseases/ or (((heart or cardiac or cardiovascular or coronory) adj (disorder? or disease? or failure)) or arrythmia?).tw.

14. exp cerebrovascular disorders/ or ((cerebrovascular or vascular or carotoid$ or arter$) adj (disorder? or disease?)).tw.

15. exp asthma/ or asthma$.tw.

16. exp pulmonary disease chronic obstructive/ or (copd or (pulmonary adj2 (disease? or disorder?))).tw.

17. exp hyperlipidemia/ or (hyperlipidem$ or hypercholesterolemia$ or hypertriglyceridemia$).tw.

18. exp Thyroid disease/ or ((thyroid adj (disease? or disorder)) or hyperthyroid$ or hypothyroid$).tw.

19. exp arthritis rheumatoid/ or rheumatoid arthritis.tw.

20. exp mental disorders/ or (((mental or anxiety or mood or psychological or sleep) adj (disease? or disorder?)) or ((substance or drug or marijuana or cocaine or amphetamine) adj2 abuse) or depression or schizophren$ or psychos$ or "substance abuse" or addictions?).tw.

21. exp epliepsy/ or (epileps$ or seizure?).tw.

22. exp hiv infections/ or (HIV or acquired immune$ deficeiency syndrom? or (aids adj (associated or related or arteritis))).tw.

23. exp neoplasms/ or (neoplasm? or cancer?).ti,ab.

24. exp osteoporosis/ or osteoporosis.tw.

25. exp kidney diseases/ or (kidney adj (disease? or disorder?)).tw.

26. exp liver disease/ or (liver adj (disease? or disorder?)).tw.

27. or/11-26

28. ((coocur$ or co-ocur$ or coexist$ or co-exist$ or multiple$) adj3 (disease? or ill$ or care or condition? or disorder$ or health$ or medication$ or symptom$ or syndrom$)).tw.

29. chronic$.ti,ab,hw.

30. 28 or 29

31. 27 and 30

32. exp education, continuing/

33. (education$ adj2 (program$ or intervention? or meeting? or session? or strateg$ or workshop? or visit?)).tw.

34. (behavio?r$ adj2 intervention?).tw.

35. pamphlets/

36. (leaflet? or booklet? or poster or posters).tw.

37. ((written or printed or oral) adj information).tw.

38. (information$ adj2 campaign).tw.

39. (education$ adj1 (method? or material?)).tw.

40. *advance directives/

41. outreach.tw.

42. ((opinion or education$ or influential) adj1 leader?).tw.

43. facilitator?.tw.

44. academic detailing.tw.

45. consensus conference?.tw.

46. *guideline adherence/

47. (guideline adj2 (introduc$ or issu$ or ipact or effect? or disseminat$ or distribut$)).tw.

48. practice guideline?.tw.

49. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 training program$).tw.

50. *reminder systems/

51. reminder?.tw.

52. (recall adj2 system$).tw.

53. (prompter? or prompting).tw.

54. algorithm?.tw.

55. *feedback/ or feedback.tw.

56. chart review$.tw.

57. ((effect? or impact or records or chart?) adj2 audit).tw.

58. compliance.tw.

59. marketing.tw.

60. or/32-59

61. exp Reimbursement Mechanisms/

62. fee for service.tw.

63. *capitation fee/

64. *"deductables and coinsurance"/

65. cost shar$.tw.

66. (copayment? or co payment?).tw.

67. (prepay$ or prepaid or prospective payment).tw.

68. *hospital charges/
69. formular?.tw.

70. fundhold?.tw.

71. *medicaid/
72. *medicare/
73. blue cros.tw.
74. 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73
75. *nurse clinicians/
76. *nurse midwives/
77. *nurse practitioners/
78. (nurse adj (rehabilitator? or clinician? or practitioner? or midw$)).tw.
79. *pharmacists/
80. clinical pharmacist/
81. paramedica?.tw.
82. *patient care team/
83. exp patient care planning/
84. (team? adj2 (care or treatment or assessment or consultation)).tw.
85. (integrat$ adj2 (care or service?)).tw.
86. (care adj2 (coordinat$ or program$ or continuity)).tw.
87. (case adj1 management).tw.
88. exp ambulatory care facilities/
89. ambulatory care/
90. 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89
91. *home care services/
92. *hospices/
93. *nursing homes/
94. *office visits/
95. *house calls/
96. *day care/
97. *aftercare/
98. *community health nursing/
99. (chang$ adj1 location).tw.
100. domiciliary.tw.
101. (home adj1 treat$).tw.
102. day surgery.tw.
103. *medical records/
104. *medical records systems, computerized/
105. (information adj2 (management or system?)).tw.
106. *peer review/
107. *utilization review/
108. exp *health services misuse/

109. or/91-108

110. *physician's practice patterns/

111. quality assurance.tw.

112. *process assessment/ [health care]

113. *program evaluation/

114. *length of stay/

115. (early adj1 discharg$).tw.

116. discharge planning.tw.

117. offset.tw.

118. triage.tw.

119. exp "Referral and Consultation"/ and "consultation"/

120. *drug therapy, computer assisted/

121. near patient testing.tw.

122. *medical history taking/

123. *telephone/

124. (physician patient adj (interaction? or relationship?)).tw.

125. *health maintenance organizations/

126. managed care.tw.

127. (hospital? adj1 merg$).tw.

128. 110 or 111 or 112 or 113 or 114 or 115 or 116 or 117 or 118 or 119 or 120 or 121 or 122 or 123 or 124 or 125 or 126 or 127

129. ((standard or usual or routine or regular or tradtiional or conventional or pattern) adj2 care).tw.

130. (program$ adj2 (reduct$ or increase$ or decreas$ or chang$ or improv$ or modify$ or monitor$ or care)).tw.

131. (program$ adj1 (health or care or intervention?)).tw.

132. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 treatment program$).tw.

133. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 care program$).tw.

134. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 screening program$).tw.

135. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 prevent$ program$).tw.

136. (computer$ adj2 (dosage or dosing or diagnosis or therapy or decision?)).tw.

137. ((introduc$ or impact or effect? or implement$ or computer$) adj2 protocol?).tw.

138. ((effect or impact or introduc$) adj2 (legislation or regulations or policy)).tw.

139. 129 or 130 or 131 or 132 or 133 or 134 or 135 or 136 or 137 or 138

140. 60 or 74 or 90 or 109 or 128 or 139

141. (case reports or clinical conference or comment or editorioal or letter).pt.

142. interviews as topic/

143. focus groups/

144. narration/

145. qualitative research/

146. (("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)).tw,kw.

147. (focus group* or qualitative or ethnograph* of fieldwork or "field work" or "key informant").kw,tw.

148. 142 or 143 or 144 or 145 or 146 or 147

149. 10 and 140 and 148

150. 31 and 140 and 149

151. 149 or 150

152. 151 not 141

Embase Search Strategy

1. comorbidity/

2. (comorbid* or co-morbid*).tw.

3. multimorbidity/

4. (multimorbid* or multi morbid* or multilpe morbid*).tw.

5. (multidisease* or multi disease? or (multiple adj (ill$ or disease? or condition? or syndrom$ or disorder?))).tw.

6. or/1-5

7. chronic disease/

8. (chronic$ adj3 (disease?or ill$ or care or condition or disorder$ or health$ or medication$ or syndrom$ or symptom$)).tw.

9. 7 or 8

10. 6 or 9

11. exp diabetes/ or diabet*.tw.

12. exp hypertension/ or (hypertens$ or "high blood pressure").tw.

13. exp heart disease/ or exp myocardial disease/ or (((heart or cardiac or cardiovascular or coronory) adj (disorder? or disease? or failure)) or arrythmia?).tw.

14. cerebrovascular disease/ or carotid artery disease/ or ((cerebrovascular or vascular or carotoid$ or arter$) adj (disorder? or disease?)).tw.

15. exp asthma/ or asthma$.tw.

16. Chronic obstructive lung disease/ or (copd or ((pulmonary or lung?) adj2 (disease? or disorder?))).tw.

17. exp hyperlipidemia/ or exp hypercholesterolemia/ or (hyperlipidem$ or Hypercholesterolemia$ or hypertriglheceridemia$).tw.

18. exp Thyroid disease/ or ((thyroid adj (disease? or disorder)) or hyperthyroid$ or hypothyroid$).tw.

19. exp rheumatoid arthritis/ or rheumatoid arthritis.tw.

20. exp mental disease/ or (((mental or anxiety or mood or psychological or sleep) adj (disease? or disorder?)) or ((substance or drug or marijuana or cocaine or amphetamine) adj2 abuse) or depression or schizophren$ or psychos$ or "sustance abuse" or addictions?).tw.

21. exp epilepsy/ or (epilep$ or seizure$).tw.

22. Human Immunodeficiency Virus/ or (HIV or acquired immune$ deficiency syndome? or (aids adj (associated or related or arteritis)) or human immunodfeiciency).tw.

23. exp neoplasm/ or (neoplasm? or cancer?).tw.

24. exp kidney disease/ or ((kidney? or renal) adj (disease? or disorder? or failure)).tw.

25. exp liver disease/ or (liver adj (disease? or disorder?)).tw.

26. exp osteoporosis/ or osteoporosis.tw.

27. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26

28. ((coocur$ or co-ocur$ or coexist$ or co-exist$ or multiple$) adj3 (disease? or ill$ or care or condition? or disorder$ or health$ or medication$ or symptom$ or syndrom$)).tw.

29. chronic$.tw.

30. 28 or 29

31. 27 and 30

32. exp primary health care/ or exp primary medical care/

33. (primary adj2 (care? or medical$ or clinic$ or parcitioner? or doctor?)).tw.

34. General practitioner/

35. (((family or general or generalist or communit$) adj2 (physician? or doctor? or practitioner? or practice?)) or GP).tw.

36. General Practice/

37. exp community care/

38. (communit$ adj2 (health or healthcare or service? or clinic$ or setting? or centre? or center?)).tw.

39. 32 or 33 or 34 or 36 or 37 or 38

40. (education$ adj2 (program$ or intervention? or meeting? or session? or strateg$ or workshop? or visit?)).tw.

41. (behavio?r$ adj2 intervention?).tw.

42. (leaflet? or booklet? or poster or posters).tw.

43. ((written or printed or oral) adj information).tw.

44. (information$ adj2 campaign).tw.

45. (education$ adj1 (method? or material?)).tw.

46. outreach.tw.

47. ((opinion or education$ or influential) adj1 leader?).tw.

48. facilitator?.tw.

49. academic detailing.tw.

50. consensus conference?.tw.

51. practice guideline?.tw.

52. (guideline? adj2 (introduc$ or issu$ or impact or effect or disseminat$ or distribut$)).tw.

53. ((introduc$ or impact or effect? or implement$ or computer$ or compli$) adj2 protocol?).tw.

54. ((introduc$ or impact or effect? or implement$ or computer$ or compli$) adj2 algorithm?).tw.

55. clinical pathway.tw.

56. critical pathway.tw.

57. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 training program$).tw.

58. reminder?.tw.

59. (recall adj2 system$).tw.

60. (prompter? or prompting).tw.

61. advance directive?.tw.

62. *feedback/ or feedback.tw.

63. chart review$.tw.

64. ((effect? or impact or records or chart?) adj2 audit).tw.

65. compliance.tw.

66. marketing.tw.

67. ((cost or clinical or medical) adj information).tw.

68. *medical education/

69. *medical audit/

70. continuing edcation/

71. postgraduate education/

72. or/40-71

73. fee for service.tw.

74. cost shar$.tw.

75. (copayment? or co payment?).tw.

76. (prepay$ or prepaid or prospective payment).tw.

77. formular?.tw.

78. fundhold.tw.

79. blue cross.tw.

80. voucher.tw.

81. (free adj2 care).tw.

82. exp *health insurance/

83. *health care costs/

84. *health care financing/

85. *medical fee/
86. *prospective payment/

87. or/73-86

88. (nurse adj (rehabilitator? or clinician? or practitioner? or midw$)).tw.

89. ((nurse or midwif$ or practitioner) adj managed).tw.

90. clinical pharmacist?.tw.

91. paramedic?.tw.

92. exp *paramedical personnel/

93. *general practitioner/

94. *physician/

95. (team? adj2 (care or treatment or assessment or consultation)).tw.

96. (integrat$ adj2 (care or service?)).tw.

97. (care adj2 (coordinat$ or program$ or continuity)).tw.

98. (case adj1 management).tw.

99. *patient care/

100. (chang$ adj1 location).tw.

101. domiciliary.tw.

102. (home adj1 (treat$ or visit?)).tw.

103. day surgery.tw.

104. exp *primary health care/

105. *ambulatory surgery/

106. *nursing home/

107. *day hospital/

108. *outpatient care/

109. *terminal care/

110. *group practice/

111. *general practice/

112. *rural health care/

113. *community mental health center/

114. information system/

115. *medical record/

116. (information adj2 (management or system?)).tw.

117. *peer review/

118. *professional standards review organization/

119. exp *clinical practice/

120. quality assurance.tw.
121. exp health care delivery/

122. *health care quality/

123. *professional practice/

124. (early adj1 discharg$).tw.

125. discharge planning.tw.

126. offset.tw.

127. triage.tw.

128. near patient testing.tw.

129. *patient referral/

130. (physician patient adj (interaction? or relationship?)).tw.

131. managed care.tw.

132. *health care organization/

133. *health maintenance organization/

134. *health care system/

135. *health care access/

136. (hospital? adj1 merg$).tw.

137. (computer$ adj2 (diagnosis or therapy)).tw.

138. (computer$ adj2 (dosage or dosing or diagnosis therapy or decision?)).tw.

139. gatekeep$.tw.

140. or/88-139

141. ((standard or usual or routine or regular or tradtiional or conventional or pattern) adj2 care).tw.

142. (program$ adj2 (reduct$ or increase$ or decreas$ or chang$ or improv$ or modify$ or monitor$ or care)).tw.

143. (program$ adj1 (health or care or intervention?)).tw.

144. ((effect or impact or introduc$) adj2 (legislation or regulations or policy)).tw.

145. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 treatment program$).tw.

146. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 care program$).tw.

147. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 screening program$).tw.

148. ((effect? or impact or evaluat$ or introduc$ or compar$) adj2 prevent$ program$).tw.

149. or/141-148

150. 72 or 87 or 140 or 149

151. (case reports or clinical conference or comment or editorioal or letter).pt.

152. (("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3(interview* or discussion* or questionnaire*)).ti,ab.

153. (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").kw,tw.

154. qualitative research/

155. 152 or 153 or 154

156. 10 and 39 and 150 and 155

157. 31 and 39 and 150 and 155

158. 156 or 157

159. 158 not 151

CINAHL search strategy

Search ID#	Search Terms	Search Options	Actions
☐	S49	S48 OR S47	**Limiters** - English Language; Exclude MEDLINE records; Hum **Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S48	(24 or 25) AND 32 AND 46	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase
☐	S47	3 and 32 and 46	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase
☐	S46	S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45	**Expanders** - Apply equivalent subjects **Search modes** - Boolean/Phrase

☐	S45	(MH "Focus Groups")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S44	(MH "Audiorecording")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S43	(MH "Field Studies")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S42	(MH "Narratives")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S41	(MH "Participant Observation")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S40	(MH "Field Notes")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S39	(MH "Constant Comparative Method")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S38	(MH "Observational Methods")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S37	(MH "Grounded Theory")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S36	(MH "Qualitative Studies")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S35	(MH "Ethnographic Research")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S34	(MH "Content Analysis") OR (MH "Thematic Analysis")	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S33	"ethnography OR qualitative OR grounded theory"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S32	S27 OR S28 OR S29 OR S30 OR S31	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S31	MW care of patient or community	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S30	MH "Community Health Services+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S29	MH "primary Health Care"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase

☐	S28	MH "Family Practice" OR (family practice or general practice or family practitioner or general practitioner or family doctor)	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S27	MH "Physicians, Family" OR TI (family physician? or family doctor?) OR AB (family physician? or family doctor?)	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S26	TI (multimorbid* or multimorbid*) OR AB (multimorbid* or multimorbid*)	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S25	S22 AND S23	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S24	S6 AND S23	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S23	TI (coocur* or coexist* or co-ocurr* or co-exist) OR AB (coocur* or coexist* or co-ocurr* or co-exist)	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S22	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S21	TI diabet* or asthma* or chronic or disease	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S20	(MW (disease or diseases)) OR MW syndrome? OR MW chronic	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S19	MM "Kidney disease+"	**Expanders** - Apply related words **Search modes** - SmartText Searching
☐	S18	MM "Liver Diseases+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S17	MM "Human Immunodeficiency virus+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S16	MH "Mental disorders, chronic" OR MM "mental disorders+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S15	MM "epilepsy+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S14	MM "Arthritis+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase

☐	S13	MM "Thyroid disease"	**Expanders** - Apply related words **Search modes** - SmartText Searching
☐	S12	MM "Thyroid diseases+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S11	MM "lungdiseases, obstructive+" OR MM "Pulmonary Disease, Chronic Obstructive+" OR MM "Asthma+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S10	MM "Cardiovascular Disease+"	**Expanders** - Apply related words **Search modes** - SmartText Searching
☐	S9	MM "Cardiovascular Disease+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S8	MM "Hypertention+" OR MM "cerebrovascular disorders+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S7	MH "Diabetes Mellitus+"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S6	S4 OR S5	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S5	TI chronic* W3 disease? or chronic* W3 ill* or chronic W3 care or chronic* W3 condition? or chronic* W3 disorder? or chronic* W2 health* or chronic* W3 medication* or chronic* W3 syndrom* or chronic* W3 symptom*	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S4	MH "Chronic Disease"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S3	S1 OR S2	**Expanders** - Apply related words **Search modes** - Boolean/Phrase

☐	S2	TI (multimorbid* or multi-morbid* or comorbid* or co-morbid* or multidisease? or multi-disease?) OR AB (multimorbid* or multi-morbid* or comorbid* or co-morbid* or multidisease? or multi-disease?) OR (TI(multiple N2 ill* or multiple N2 disease? or multiple N2 condition? or multiple N2 syndrom* or multiple N2 disorder?) or AB(multiple N2 ill* or multiple N2 disease? or multiple N2 condition? or multiple N2 syndrom* or multiple N2 disorder?))	**Expanders** - Apply related words **Search modes** - Boolean/Phrase
☐	S1	MH "Comorbidity"	**Expanders** - Apply related words **Search modes** - Boolean/Phrase

Cochrane search strategy

ID Search

#1 MeSH descriptor: [Comorbidity] this term only

#2 (comorbid* or co-morbid* or multimorbid* or multi-morbid* or multidisease or multidiseases or multi-disease or multi-diseases):ti

#3 MeSH descriptor: [Hospitals, Chronic Disease] explode all trees #4 #1 or #2 or (#2 and #3)

#5 MeSH descriptor: [Hypertension] explode all trees

#6 MeSH descriptor: [Diabetes Mellitus] 1 tree(s) exploded #7 diabet*:ti,ab

#8 (hypertens* or "high blood pressure"):ti,ab

#9 MeSH descriptor: [Heart Diseases] explode all trees

#10 MeSH descriptor: [Cerebrovascular Disorders] 1 tree(s) exploded

#11 (cerebrovascular disorder* or cerebrovascular disease* or vascular disorder* or vascular disease* or carotoid* disorder* or carotoid disease* or arter* disorder* or arter* disease*):ti

#12 MeSH descriptor: [Asthma] 2 tree(s) exploded #13 asthma*:ti

#14 MeSH descriptor: [Pulmonary Disease, Chronic Obstructive] explode all trees #15 (copd or pulmonary disease* or pulmonary disorder*):ti

#16 MeSH descriptor: [Hyperlipidemias] explode all trees

#17 (hyperlipidem* or Hypercholesterolemia* or hypertriglyceridemia*):ti #18 MeSH descriptor: [Thyroid Diseases] explode all trees

#19 (thyroid disease* or thyroid disorder*):ti

#20 MeSH descriptor: [Mental Disorders] explode all trees

#21 ((mental or anxiety or mood or psychological or sleep) near/2 (disease* or disorder*)):ti #22 ((substance or drug or marijuana or cocaine or Amphetamine) near/2 abuse):ti

#23 (depression or schizophren* or psychos* or "substance abuse" or addiction or addictions):ti #24 MeSH descriptor: [Epilepsy] explode all trees

#25 (epileps* or seizure or seizures):ti

#26 MeSH descriptor: [HIV Infections] 3 tree(s) exploded #27 (HIV or acquired immune* deficiency syndrome*):ti #28 MeSH descriptor: [Neoplasms] explode all trees

#29 (neoplasm or cancer):ti

#30 MeSH descriptor: [Kidney Diseases] explode all trees #31 (kidney disease* or kidney disorder*):ti

#32 MeSH descriptor: [Liver Diseases] explode all trees #33 (liver disease* or liver disorder*):ti

#34 MeSH descriptor: [Osteoporosis] explode all trees #35 osteoporosis:ti

#36 #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or

#19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or

#33 or #34 or #35

#37 ((coocur* or co-ocur* or coexist* or co-exist* or multipl*) near/2 (disease or diseases or ill* or care or condition or conditions or disorder* or health* or medication* or symptom* or syndrom*)):ti,ab

#38 #36 and #37

#39 #4 or #38

#40 (qualitative*):ti,ab,kw

#41 MeSH descriptor: [Qualitative Research] this term only

#42 MeSH descriptor: [Evaluation Studies as Topic] explode all trees #43
#40 or #41 or #42

#43 #40 or #41 or #42

#44 #39 and #43

Appendix 3: Data Extraction Form for Systematic Review

Paper Title	
Authors	
Date of Publication	
Location of Intervention **(**Country of Origin, region, any particular reasons area chosen, any other geographical information?)	
Target population (original Intervention (including who was targeted – and why. Please record age/sex/ socioeoconmic status and any other demographics of population studied)	
Target Population (qualitative study – if different) (How participants selected from original group, please list demographics of study group as above)	
Method (How was data collected, who collected, is there a theoretical perspective in analysis (e.g.,	

IPA/grounded theory), is an external theory/framework applied during analysis)	
How is multimorbidity defined? Is this comorbidity?	
Describe the intervention (please include who delivers it (and their training), what happens, what does the participant have to do, what does the practitioner have to do?	
How does the intervention deal with non-engagers? Does the paper explore those who did not benefit? (are they included in qualitative analysis? If so, are there any themes/reasons identified for not participating)	
How was the intervention evaluated?	
What are the main outcomes of the intervention?	
What are the Secondary outcomes if any?	

What are the key findings from the qualitative analysis of patient experience?	
What are the key findings from the qualitative analysis of professional experience?	
Does this intervention attempt to “measure” patient work, or capacity in any way?	
Does this intervention increase or decrease or have no impact on treatment burden?	
Does this intervention increase or decrease or have no impact on participant capacity?	
Does this intervention have any components of self-management? If so can you categorise them using the PRISM taxonomy?(Pearce et al., 2016)	
Does this intervention take participant’s social context into account in any way? How?	
Would you need to go back to the study protocol/findings to answer some of these questions?	
Anything else you think interesting, or that strikes you not already covered?	

Appendix 4 Invitation letters

NHS
Greater Glasgow and Clyde

University of Glasgow
College of Medical, Veterinary & Life Sciences

2nd May 2022
IRAS Number: **272255**

Mosaic: how local communities help people living with illness

We would like to invite you to take part in a research study. We know that some people find managing illness easier than others and that where you live can make a difference. We want to find out more about Drumchapel and how the local community supports people living with illnesses.

We have put together an information sheet that gives more details about the study and what it involves. Please have a look at this information before you decide whether you would like to take part.

If you decide to take part, our researcher will organise a time to speak to you about how you live with and manage your illnesses (like asthma, diabetes, heart disease, depression) and what things help you or make it harder. Our researcher is interested in your experience. It is important to stress that this is not a test.

Our researcher will visit you at home, if that is convenient for you, or arrange another place that is easy for you. Alternatively, we can conduct the interview by telephone, or via video conferencing platform. We expect that the discussion will take about an hour. We will not ask you to do anything else but if you are interested we will tell you more about the study and other ways that you can be involved. It is important to remember that you don't have to take part in any other parts of the study.

To compensate you for your time and to say thanks for helping with our study, we would like to offer you a £25 supermarket voucher as well as any travel expenses you may have.

If you are interested in taking part in this study, or have any questions about the study, please call or text Marianne McCallum on XXXXX XXX XXX (leave a message if goes to answering machine) or email marianne.mccallum@glasgow.ac.uk. She will be happy to talk to you about the study. Alternatively, you can return the reply slip on the following page and return it in the prepaid envelope.

Thank you for reading this.

Yours sincerely,

Dr Marianne McCallum
GP Clinical Academic Fellow
University of Glasgow

University of Glasgow | Institute of Health & Wellbeing

NHS Greater Glasgow and Clyde

Reply Slip

MOSAIC: how local communities help people living with illness

☐ **I am interested in taking part in the interview study. Please phone me to arrange a time for the interview.**

Name: ______________________________

Telephone: ______________________________

☐ **I am happy for the researcher to leave a message on my phone if necessary.**

Address: ______________________________

____

____

Please return in the prepaid envelope to Dr Marianne McCallum

NHS
Greater Glasgow and Clyde

University of Glasgow
College of Medical, Veterinary & Life Sciences

16th November 2022
IRAS Number: 272255

Dear

Mosaic: how local communities help people living with illness

We are very grateful for the interview you gave to us previously as part of our study (Mosaic: Multimorbidity in the context of socioeconomic deprivation: a mixed methods exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity) looking at how the local community helps people living with illness. We are writing to you because at the time of the interview we explained that we hoped to arrange some group discussions to discuss some of our findings with people from the community.

We have put together an information sheet that gives more details about what these group discussions involve. Please have a look at this information before you decide whether you would like to take part.

If you decide to take part, our researcher will organise a time for you to take part in our group discussions. We expect that the discussion will take about an hour.

To compensate you for your time and to say thanks for helping with our study, we would like to offer you £25 supermarket voucher as well as any travel expenses you may have.

If you are interested in taking part in this study, or have any questions about the study, please call or text Marianne McCallum on xxxx xxx xxx or email marianne.mccallum@glasgow.ac.uk. She will be happy to talk to you about the study. Alternatively, you can return the reply slip on the following page and return it in the enclosed envelope.

Thank you for reading this.

Yours sincerely,

Dr Marianne McCallum
GP Clinical Academic Fellow
University of Glasgow

University of Glasgow | Institute of Health & Wellbeing

NHS Greater Glasgow and Clyde

Reply Slip

Mosaic: how local communities help people living with illness

☐ **I am interested in taking part in the group discussions. Please phone me to arrange a time for the interview.**

Name: ____

Telephone: ____

☐ **I am happy for the researcher to leave a message on my phone if necessary.**

Address: ____

____

____

Please return in the FREEPOST envelope in the enclosed envelope.

Appendix 5: Participant Information Sheets

Participant Observation:

University of Glasgow | College of Medical, Veterinary & Life Sciences

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. If you decide to take part in this study, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

1. What is the purpose of the study?

Managing illnesses can be hard work: we know some people find it easier than others and that the community you live in can make a difference. Having support from friends and family, transport or knowing how to cope with illness are all important but we don’t know whether they are more important for some people than others. People living in areas experiencing socio-economic deprivation are more likely to struggle to manage their illnesses.

The purpose of this study is to gain a deeper understanding of the key factors that influence people's ability to manage multiple long-term conditions, particularly the role that community resources and health beliefs play in this, when they are living in areas experiencing the negative impact of poverty. Better understanding of these factors will allow us to design services and support for patients that will ensure we are better able to meet the needs, and reduce the barriers, poverty can create for people in managing their chronic illnesses.

We plan to do this by spending time in Drumchapel, observing different community services and how patients use them.

This study is part of a PhD being carried out by one of the academic GPs at Glasgow University: Dr Marianne McCallum

2. Why have I been invited to participate?

Your group, or project, has been invited to take part in this study because it has been identified by people living or working in Drumchapel as a key asset within the community. Key assets are groups or services that local residents think make an important contribution to the community. We want to know how your service works, how residents use it and how it helps them manage their long-term illnesses.

You can be in this study if:

- you are a project open to residents living in Drumchapel

- Your project supports adults (over age 18).

3. Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

4. What will happen to me if I take part?

If you agree to take part the lead researcher would meet you to clarify the study's aims and answer any questions. If you are willing for your project to take part, we will ask to have one of the researchers attend the service, in person, or online as depending on local restrictions, and see how it works. Prior to them attending we would ask you to get verbal consent from all your clients that they are happy for the researcher to attend. It may be that the researcher will visit the service several times to gather as much information as possible. Any notes or observations that the researcher makes will be stored securely in a password protected computer and in line with University of Glasgow research governance policy

When the researcher visits the service we would like to carry out some short interviews to gather more detailed information. We will ask some of those using the service but it is important to stress that they do not have to participate in the interview if they would rather not. If you are aware of any group participants who it would not be suitable to interview further, then this will be respected and they would not be approached.

In addition, if you are willing, we would also like to take the opportunity to interview you regarding your understanding and experience of resources in Drumchapel and how your clients use them. We would expect this to take about 30 minutes over the phone, zoom or at your group premises. This interview is not compulsory, your group can take part in this study without you being interviewed.

We will also be running five asset-based workshops, once current restrictions allow it, to understand local views on key community assets in Drumchapel. We will invite some of your service users and may ask if it is suitable for them to take part. If you feel there are, we would ask you to ask if they would consider taking part, and if they are ok for you to pass their details on to the research team. This recruitment is not compulsory, if you do not wish, or do not feel it is appropriate for your clients to take part in these workshops your groups can still take part in the other parts of this study.

This observation is part of a wider study, due to finish in early 2023, during which the main researcher will, spend two years in Drumchapel seeking to understand how people use personal and community resources to manage their long-term illnesses. As well as observing community groups we plan on doing interviews and focus groups with patients.

5. What do I have to do?

If you are willing for your group to take part we would ask you to obtain verbal permission for the researcher to attend your group or project, in person or online and observe how your clients use it. In addition, if you wish the researcher may want to carry out a short interview regarding your thoughts about the local services and how people use the. We also may ask if you have any clients who may be suitable to take part in an asset-based workshop.

6. What are the possible disadvantages and risks of taking part?

We recognise we may be discussing and collecting potentially sensitive data regarding your client's health conditions. We will follow all relevant legislation in managing and processing this data and attach a privacy notice so you can understand exactly how this data will be processed and stored.

7. What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. However, the information that is collected during this study will give us a better understanding of what helps support people to manage their health conditions, and what makes it harder. This information can be used to design services and supports that may better meet the needs of your clients.

8. Will my taking part in this study be kept confidential?

- All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. Your group will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

- Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password–protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

9. What will happen to my data?

- We may be collecting and storing identifiable information from you in order to undertake this study. This means that the University is responsible for looking after your information and using it properly. We may keep identifiable information about your group, including your contact details, for ten years after the study ends, we will not pass this information to a third party without your express permission.
- Your rights to access, change or move the information we store may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information from marianne.mccallum@glasgow.ac.uk.

- Researchers from the University of Glasgow collect, store and process all personal information in accordance with the General Data Protection Regulation (2018).
- All study data will be held in accordance with The General Data Protection Regulation (2018)
- The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, identifiable data (such as field notes) will be securely destroyed Any anonymised transcripts will be archived in a secure data archive run by the University of Glasgow. In the future other researches may be able to look at these transcripts, but only after obtaining scientific and ethical consent.
- Your identifiable information might be shared with people who check that the study is done properly and, if you agree, in coded form with other organisations or universities to carry out research to improve scientific understanding. Your data will form part of the study result that will be published in expert journals, presentations, student theses and on the internet for other researchers to use. Your name will not appear in any publication.

10. What will happen to the results of the research study?

The results of the study will be published in expert journals, presented at academic conferences and be used in Dr McCallum's thesis for her PhD. We also plan to feedback the findings of our research to the community in form of a presentation at an open community meeting at the end of the study. Direct quotes from the transcripts of the interviews may be used in these publications – these will be presented anonymously with no information that would be able to link these comments to yourself.

When are the results likely to be published? Where can they obtain a copy of the published results?

11. Who is organising and funding the research?

This research is being funded by the Chief Scientist's Office in the Scottish Government.

12. Who has reviewed the study?

The project has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee.

13. Contact for Further Information

Thank you for reading this information sheet, if you have any further questions please contact:
Dr Marianne McCallum: marianne.mccallum@glasgow.ac.uk.

Asset based workshop

University of Glasgow | College of Medical, Veterinary & Life Sciences

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. If you decide to take part in this study, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

14. What is the purpose of the study?

Managing illnesses can be hard work: we know some people find it easier than others and that the community you live in can make a difference. Having support from friends and family, transport or knowing how to cope with illness are all important but we don't know whether they are more important for some people than others. People living in areas experiencing socio-economic deprivation are more likely to struggle to manage their illnesses.

The purpose of this study is to understanding how people manage multiple long-term conditions (which doctors call multmorbidity) and what helps them when they live in areas experiencing the negative impact of poverty. This will help us to design services and supports for patients that meet their needs and reduce the barriers that poverty can create for people when managing their illnesses.

We want to know what residents in Drumchapel think are important community resources (or assets). To find this out we plan to hold workshops with local residents which will help us to identify local services and resources. In the workshops groups of people from the local community will work together to identify what they feel are the key assets within their community.

This study is part of a PhD being carried out by one of the academic GPs at Glasgow University: Dr Marianne McCallum

15. Why have I been invited to participate?

You have been invited to take part in one of these workshops as the manager of [specify the local group] you attend has suggested you may be willing to be involved.
You can be in this study if:

- you are over 18 years old
- you have two or more long-term conditions (this can include physical and mental health problems)

- You speak and understand English (Unfortunately we do not have a budget for translators)
- You have lived in Drumchapel for at least the last 18 months.

16. Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason.

17. What will happen to me if I take part?

If you would be willing to consider taking part one of our researchers will contact you, this gives you a chance to ask us any questions. If you are happy to proceed then we will arrange for you attend one of the workshops. These will take place at a central community venue in Drumchapel. The workshop will last an afternoon and lunch will be provided. During the workshop we will have group discussions and do a variety of exercises to explore local assets. During this we want to understand your views or opinions, particularly what YOU think is important and helpful in your community. We will record the workshop on a digital recorder, and the workshop will be led by one of the researchers. We hope to recruit 6 to 8 people to each group.

The recordings from the workshop will be typed up and any identifying information (names, addresses) will be removed. The transcript will be stored on a secure university server.

These workshops are part of a wider study, due to finish in September 2022. After the workshops the lead researcher plans on visiting some of the identified services to try to understand how people use personal and community resources to manage their long-term illnesses.

18. What are the possible disadvantages and risks of taking part?

We recognise that different people will have different experiences and there may be disagreement during the discussions. The facilitator will explain clear group rules before beginning the discussion, and it is important that everyone's view is respected and everyone has a chance to give their opinion.

Because we will be discussing and collecting data regarding your health conditions and experiences, which you might find sensitive, we will make sure that we follow all relevant legislation in managing and processing this data. We will provide you with a privacy notice so that you know exactly how this data will be processed and stored.

19. What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. However, the information that is collected during this study will give us a better understanding of what helps support people to manage their health conditions, and what makes it harder. This information may be used to design services and supports that better meet the needs of patients.

20. Will my taking part in this study be kept confidential?

- All information which is collected about you, or responses that you provide, during the workshops will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

- Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password–protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

21. What will happen to my data?

- We may be collecting and storing identifiable information from you in order to undertake this study. This means that the University is responsible for looking after your information and using it properly. We may keep identifiable information about you for five years after the study ends, we will not pass this information to a third party without your express permission.
- Your rights to access, change or move the information we store may be limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information from [Principal Investigator contact details].
- Researchers from the University of Glasgow collect, store and process all personal information in accordance with the General Data Protection Regulation (2018).
- All study data will be held in accordance with The General Data Protection Regulation (2018)
- The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 5 years. After this period, identifiable data (such as field notes) will be securely destroyed Any anonymised transcripts will be archived in a secure data archive run by the University of Glasgow. In the future other researches may be able to look at these transcripts, but only after obtaining scientific and ethical consent.

- Your identifiable information might be shared with people who check that the study is done properly and, if you agree, in coded form with other organisations or universities to carry out research to improve scientific understanding. Your data will form part of the study result that will be published in expert journals, presentations, student theses and on the internet for other researchers to use. Your name will not appear in any publication.

22. What will happen to the results of the research study?

The results of the study will be published in expert journals, presented at academic conferences and be used in Dr McCallum's thesis for her PhD. We also plan to feedback the findings of our research to the community in form of a presentation at an open community meeting at the end of the study. Direct quotes from the transcripts of the interviews may be used in these publications – these will be presented anonymously with no information that would be able to link your information with these comments.

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23. Who is organising and funding the research?

This research is being funded by the Chief Scientist's Office in the Scottish Government.

24. Who has reviewed the study?

The project has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee.

25. Contact for Further Information

Thank you for reading this information sheet, if you have any further questions please contact:
Dr Marianne McCallum: marianne.mccallum@glasgow.ac.uk Tel: xxxxx xxx xxx

Interviews

NHS
Greater Glasgow
and Clyde

University of Glasgow
College of Medical, Veterinary & Life Sciences

IRAS Number: 272255

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. If you decide to take part in this study, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

26. What is the purpose of the study?

Managing illnesses can be hard work: we know some people find it easier than others and that the community you live in can make a difference. Having support from friends and family, transport or knowing how to cope with illness are all important but we don’t know whether they are more important for some people than others. People living in areas experiencing socio-economic deprivation are more likely to struggle to manage their illnesses.

The purpose of this study is to gain a deeper understanding of the key factors that influence people's ability to manage multiple long-term conditions (which doctors call multmorbidity) when they are living in areas experiencing the negative impact of poverty. Better understanding of these factors will allow us to design services and support for patients that will ensure we are better able to meet the needs, and reduce barriers, poverty can create for people in managing their chronic illnesses. We plan to do this by interviewing people with multiple long-term conditions who live in Drumchapel.

This study is part of a PhD being carried out by one of the academic GPs at Glasgow University: Dr Marianne McCallum.

27. Why have I been invited to participate?

You have been invited to take part in this study because you have three or more long-term medical conditions and are a current resident of Drumchapel. We are keen to understand what things make managing multiple long-term conditions easier, or more difficult, for people currently living in Drumchapel.

You can only be in this study if:

- you are over 18 years old
- you have three or more long-term conditions (this can include things like high blood pressure)
- You speak and understand English (Unfortunately we do not have a budget for translators)
- You have lived in Drumchapel for at least the last 18 months.

28. Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

29. What will happen to me if I take part?

If you take part one of our researchers will contact you, this gives you a chance to ask us any questions. If you are happy to proceed they will arrange a date and time to do the interview; this can either be via telephone, at your home, or at a central community venue. The choice of venue is whatever suits you best.

The interview will last approximately an hour and will be recorded on a digital recorder. The interviewer will ask you about your experience of managing your long-term conditions and what sorts of things, including community resources, have been helpful, as well as what has made it harder. We will pay for travel expenses if required, and we will give you a £25 gift voucher to recompense you for your time.

The recordings from the interview will be typed up and any identifying information (name, address) will be removed. The transcript will be stored on a secure university server.

These interviews are part of a wider study, where the main researcher will spend two years in Drumchapel to understand how people use personal and community resources to manage their long-term illnesses.

During the interview you will be asked if you are happy to be contacted in 12 to 18 months to take part in a group discussion to discuss community and personal resources in Drumchapel. Participation in this further group is entirely voluntary, you can choose to take part in the interview without taking part in the later group discussion. We hope to recruit and interview 30 patients.

30. What do I have to do?

We would ask you to take part in the interview, but otherwise you do not need to make any changes to your current medication or management of your health conditions.

31. What are the possible disadvantages and risks of taking part?

Some people find it difficult to talk about their health, particularly if they have had negative experiences of health care.

We recognise we will be discussing and collecting potentially sensitive data regarding your health conditions. We will follow all relevant legislation in managing and processing this data and attach a privacy notice so you can understand exactly how this data will be processed and stored.

32. What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. However, the information that is collected during this study will give us a better understanding of what helps support people to manage their health conditions, and what makes it harder. This information can be used to design services and supports that better meet the needs of patients.

33. Will my taking part in this study be kept confidential?

- All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

- Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password–protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

34. What will happen to my data?

- NHS Greater Glasgow and Clyde is the sponsor for this study based in the UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. NHS Greater Glasgow and Clyde will keep identifiable information about you for 10 years after the study has finished.
- Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.
- You can find out more about how we use your information https://www.nhsggc.org.uk/patients-and-visitors/faqs/data-protection-privacy/

- Researchers from the University of Glasgow collect, store and process all personal information in accordance with the General Data Protection Regulation (2018).
- All study data will be held in accordance with The General Data Protection Regulation (2018)
- The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed or your data will be securely destroyed in accordance with the relevant standard procedures.
- Your identifiable information might be shared with people who check that the study is done properly and, if you agree, in coded form with other organisations or universities to carry out research to improve scientific understanding. Your data will form part of the study result that will be published in expert journals, presentations, student theses and on the internet for other researchers to use. Your name will not appear in any publication.

35. What will happen to the results of the research study?

The results of the study will be published in expert journals, presented at academic conferences and be used in Dr McCallum's thesis for her PhD. We also plan to feedback the findings of our research to the community in form of a presentation at an open community meeting at the end of the study. Direct quotes from the transcripts of the interviews may be used in these publications – these will be presented anonymously with no information that would be able to link these comments to yourself.

36. Who is organising and funding the research?

This research is being funded by the Chief Scientist's Office in the Scottish Government.

37. Who has reviewed the study?

The project has been reviewed by the NHS West Midlands Solihull Research Ethics committee.

38. Contact for Further Information

Thank you for reading this information sheet, if you have any further questions please contact:
Dr Marianne McCallum: marianne.mccallum@glasgow.ac.uk. Tel: xxxxxxxxxxx (text or leave a message if goes to answering machine)

Focus Groups

IRAS number: 272255

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. If you decide to take part in this study, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

39. What is the purpose of the study?

Managing illnesses can be hard work: we know some people find it easier than others and that the community you live in can make a difference. Having support from friends and family, transport or knowing how to cope with illness are all important but we don't know whether they are more important for some people than others. People living in areas experiencing socio-economic deprivation are more likely to struggle to manage their illnesses.

The purpose of this study is to gain a deeper understanding of the key factors that influence people's ability to manage multiple long-term conditions (which doctors call multmorbidity) when they are living in areas experiencing the negative impact of poverty. Better understanding of these factors will allow us to design services and support for patients that will ensure we are better able to meet the needs, and reduce barriers, poverty can create for people in managing their chronic illnesses.

This study is part of a PhD being carried out by one of the academic GPs at Glasgow University: Dr Marianne McCallum.

40. Why have I been invited to participate?

Previously you agreed to be interviewed about your experiences managing your health conditions. Since the original interviews we have spent time in Drumchapel observing how people use community services and trying to understand local community resources and health beliefs. We are keen to discuss our findings with the people we originally interviewed to explore if our findings are similar to your own experience, and to discuss how you have, or haven't, used community resources to help manage your health. To do this we plan to hold two group discussions and we are inviting you to take

part in a group discussions because when you were originally interviewed you indicated you would be willing to contacted, and would consider taking part.
You can only be in this study if:

- you are over 18 years old
- you have three or more long-term conditions (this can include things like high blood pressure)
- You speak and understand English (Unfortunately we do not have a budget for translators)
- You have lived in Drumchapel for at least the last 18 months.

41. Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

42. What will happen to me if I take part?

If you would be willing to consider taking part one of our researchers will contact you, this gives you a chance to ask us any questions. If you are happy to proceed they will arrange for you to attend one of two focus groups which will be held at a central community venue. This may change if needed due to COVID restrictions to being via telephone or an online platform (zoom).

The focus group will last approximately an hour to an hour and a half and will be recorded on a digital recorder. One of the researchers will facilitate the discussions and will ask the group to discuss our findings and your experience of using community resources in managing your long-term conditions. We will pay for travel expenses if required, and we will give you a £25 gift voucher to recompense you for your time. We hope to recruit 6 to 8 people to each group.

The recordings from the focus group will be typed up and any identifying information (names, addresses) will be removed. The transcript will be stored on a secure university server.

These focus groups are part of a wider study, due to finish in September 2022, during which the main researcher has, and will, spend two years in Drumchapel to understand how people use personal and community resources to manage their long-term illnesses.

43. What do I have to do?

We would ask you to attend the focus group, but do not require you do anything else for this part of the study.

44. What are the possible disadvantages and risks of taking part?

We recognise that different people will have different experiences and there may be disagreement during the discussion. The facilitator will explain clear group rules before beginning the discussion, particularly regarding respecting everyone’s views to ensure that everyone is able to give their opinion, and confidentiality out with the focus group of other people's information.

We recognise we will be discussing and collecting potentially sensitive data regarding your health conditions. We will follow all relevant legislation in managing and processing this data.

45. What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. However, the information that is collected during this study will give us a better understanding of what helps support people to manage their health conditions, and what makes it harder. This information may be used to design services and supports that better meet the needs of patients.

46. Will my taking part in this study be kept confidential?

- All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

- Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password–protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

47. What will happen to my data?

- NHS Greater Glasgow and Clyde is the sponsor for this study based in the UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. NHS Greater Glasgow and Clyde will keep identifiable information about you for 10 years after the study has finished.
- Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

- You can find out more about how we use your information https://www.nhsggc.org.uk/patients-and-visitors/faqs/data-protection-privacy/

- Researchers from the University of Glasgow collect, store and process all personal information in accordance with the General Data Protection Regulation (2018).
- All study data will be held in accordance with The General Data Protection Regulation (2018)
- The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed or your data will be securely destroyed in accordance with the relevant standard procedures.
- Your identifiable information might be shared with people who check that the study is done properly and, if you agree, in coded form with other organisations or universities to carry out research to improve scientific understanding. Your data will form part of the study result that will be published in expert journals, presentations, student theses and on the internet for other researchers to use. Your name will not appear in any publication.

48. What will happen to the results of the research study?

The results of the study will be published in expert journals, presented at academic conferences and be used in Dr McCallum's thesis for her PhD. We also plan to feedback the findings of our research to the community in form of a presentation at an open community meeting at the end of the study. Direct quotes from the transcripts of the interviews may be used in these publications – these will be presented anonymously with no information that would be able to link these comments to yourself.

49. Who is organising and funding the research?

This research is being funded by the Chief Scientist's Office in the Scottish Government.

50. Who has reviewed the study?

The project has been reviewed by the West of Scotland NHS Research Ethics Committee.

51. Contact for Further Information

Thank you for reading this information sheet, if you have any further questions please contact:
Dr Marianne McCallum: marianne.mccallum@glasgow.ac.uk. Tel: xxxxxxxxxxx

Appendix 6: Consent Forms

NHS
Greater Glasgow and Clyde

University of Glasgow
College of Medical, Veterinary & Life Sciences

Centre Number: GN20HS047

IRAS Project Number:
272255

Participant Identification Number for this trial:

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

Dr Marianne McCallum (Supervisors Dr Sara MacDonald, Professor Frances Mair)

CONSENT FORM INTERVIEWS

Please initial box

I confirm that I have read and understood the Participant Information Sheet (interviews) version 2.0 dated 20/01/21. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations. ☐

I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers. ☐

I agree that my name, contact details and data described in the information sheet will be kept for 10 years for the purposes of this research project. ☐

I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study. ☐

I agree to my interview being audio-recorded. ☐

I am willing to conduct the interview using telephone or an online platform, if not able to do so face to face. ☐

I understand that the recorded interview group will be transcribed word by word and the transcription stored for up to 10 years in University archiving facilities in accordance with Data Protection policies and regulations. ☐

I understand that my information and things that I say in an interview may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed. ☐

I agree to be contacted by the research team in around 12- 18months' time about taking part in a focus group. ☐

I agree for the data I provide to be anonymously archived in the UK data archive or other approved archiving facilities, and that other researchers can have access to this data only if they have scientific and ethical approval, and agree to preserve the confidentiality of this information as set out in this form. ☐

I agree that should significant concerns regarding my mental or physical health arise during my participation in the study that a member of an appropriate clinical team will be immediately informed. ☐

I understand that any criminal acts which come to light as a result of my participation in this study may have to be reported appropriately to the relevant authorities by the research team. ☐

I understand my medical care will not be affected in anyway, whether I participate in this study or not ☐

I agree to take part in the study. ☐

________________________ ____________ ______________________

12.6.1.1 Name of participant Date Signature

________________________ ____________ ______________________

12.6.1.2 Name of Person taking consent Date Signature

(if different from researcher)

________________________ ____________ ______________________

12.6.1.3 Researcher Date Signature

(1 copy for participant; 1 copy for researcher)

NHS
Greater Glasgow and Clyde

University of Glasgow
College of Medical, Veterinary & Life Sciences

Centre Number: GN20HS047

IRAS Project Number:
272255

Participant Identification Number for this trial:

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

Dr Marianne McCallum (Supervisors Dr Sara MacDonald, Professor Frances Mair)

CONSENT FORM FOCUS GROUPS

Please initial box

I confirm that I have read and understood the Participant Information Sheet (focus group) version 2.0 dated 20/01/2021. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations. ☐

I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers. ☐

I agree that my name, contact details and data described in the information sheet will be kept for 10 years for the purposes of this research project. ☐

I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study. ☐

I agree to take part in a focus group and it being audio-recorded. ☐

I am willing to conduct the focus group using telephone or an online platform, if not able to do so face to face. ☐

I understand that the recorded focus group will be transcribed word by word and the transcription stored for up to 10 years in University archiving facilities in accordance with Data Protection policies and regulations. ☐

I understand that my information and things that I say in the focus group may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed. ☐

I agree for the data I provide to be anonymously archived in the UK data archive or other approved archiving facilities, and that other researchers can have access to this data only if they have scientific and ethical approval, and agree to preserve the confidentiality of this information as set out in this form. ☐

I agree that should significant concerns regarding my mental or physical health arise during my participation in the study that a member of an appropriate clinical team will be immediately informed. ☐

I understand that any criminal acts which come to light as a result of my participation in this study may have to be reported appropriately to the relevant authorities by the research team. ☐

I understand my medical care will not be affected in anyway, whether I participate in this study or not ☐

I agree to take part in the study. ☐

______________________________ ____________ ________________________

12.6.1.4 Name of participant **Date** **Signature**

______________________________ ____________ ________________________

12.6.1.5 Name of Person taking consent **Date** **Signature**

(if different from researcher)

______________________________ ____________ ________________________

12.6.1.6 Researcher **Date** **Signature**

(1 copy for participant; 1 copy for researcher)

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:

Project Number: CAF/19/05

Participant Identification Number for this trial:

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

Dr Marianne McCallum (Supervisors Dr Sara Macdonald, Professor Frances Mair)

CONSENT FORM ASSET BASED WORKSHOP

	Please initial box
I confirm that I have read and understood the Participant Information Sheet version 1.0	☐
I confirm that I have read and understood the Privacy Notice version 1.0	☐
I have had the opportunity to think about the information and ask questions, and understand the answers I have been given.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.	☐
I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.	☐
I agree that my name, contact details and the information I provide will be kept for the purposes of this research project.	☐
I understand that if I withdraw from the study, my data collected up to that point will be retained and used for the remainder of the study.	☐
I agree to the asset-based workshop to be audio-recorded	☐

I understand that the recordings will be transcribed word by word and the transcription stored for up to 10 years in University archiving facilities in accordance with Data Protection policies and regulations. ☐

I understand that my information and things that I say in during the workshop and group discussion may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed. ☐

I agree for the data I provide to be anonymously archived in the UK data archive or other approved archiving facilities, and that other researchers can have access to this data only if they have scientific and ethical approval and agree to preserve the confidentiality of this information as set out in this form. ☐

I agree that should significant concerns regarding my mental or physical health arise during my participation in the study that a member of an appropriate clinical team will be immediately informed. ☐

I understand that any criminal acts which come to light as a result of my participation in this study may have to be reported appropriately to the relevant authorities by the research team. ☐

I agree to take part in the study. ☐

______________________________ ____________ ______________________

12.6.1.7 Name of participant **Date** **Signature**

______________________________ ____________ ______________________

12.6.1.8 Name of Person taking consent **Date** **Signature**

(if different from researcher)

______________________________ ____________ ______________________

12.6.1.9 Researcher **Date** **Signature**

(1 copy for participant; 1 copy for researcher)

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:

Project Number: CAF/19/05

Participant Identification Number for this trial:

Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity (MOSAIC)

Dr Marianne McCallum (Supervisors Dr Sara Macdonald, Professor Frances Mair)

CONSENT FORM Participant Observation

	Please initial box
I confirm that I have read and understood the Participant Information Sheet version 1.1 dated 09'/09/2020.	☐
I confirm that I have read and understood the Privacy Notice version 1.1 dated 09/09/20.	☐
I have had the opportunity to think about the information and ask questions and understand the answers I have been given.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
I agree that should significant concerns regarding my mental or physical health arise during my participation in the study that a member of an appropriate clinical team will be immediately informed.	☐
I understand that any criminal acts which come to light as a result of participation in this study may have to be reported appropriately to the relevant authorities by the research team.	☐
I confirm that I agree to the way my organisation's data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.	☐
I understand that all data and information generated by observing my organisation will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.	☐

I understand that if I withdraw from the study, my organisation's data collected up to that point will be retained and used for the remainder of the study. ☐

I agree that my organisation's name, contact details and data described in the information sheet will be kept for the purposes of this research project.

I agree to take part in the study.

Name of participant Date Signature

Name of Person taking consent Date Signature
(if different from researcher)

Researcher Date Signature
(1 copy for participant; 1 copy for researcher)

Appendix 7: NHS Ethics application approval correspondence

NHS
Health Research
Authority

West Midlands - Solihull Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: xxxx xxx xxx

14 April 2021

Dr Marianne McCallum
General Practice and Primary Care
1 Horselethill Road
Glasgow
G12 9LX

Dear Dr McCallum

Study title:	**Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity**
REC reference:	**21/WM/0079**
IRAS project ID:	**272255**

Thank you for your letter of 24 March submitted 14 April 2021. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 March 2021.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
IRAS Application Form [IRAS_Form_14042021]		14 April 2021
IRAS Application Form XML file [IRAS_Form_14042021]		14 April 2021
IRAS Checklist XML [Checklist_14042021]		14 April 2021

Other [Invitation letter from GPs]	1.0	24 March 2021
Other [Response to conditions]	1.0	24 March 2021
Other [Consent form focus groups]	3.0	24 March 2021
Participant consent form [Consent form for interviews]	3.0	24 March 2021

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [topic guide focus group]	2	20 January 2021
IRAS Application Form [IRAS_Form_14042021]		14 April 2021
IRAS Application Form XML file [IRAS_Form_14042021]		14 April 2021
IRAS Checklist XML [Checklist_14042021]		14 April 2021
Letter from funder		
Letters of invitation to participant [invitation letter]	2	20 January 2021
Other [Consent form focus groups]	3.0	24 March 2021
Other [Invitation letter from GPs]	1.0	24 March 2021
Other [Response to conditions]	1.0	24 March 2021
Participant consent form [Consent form for interviews]	3.0	24 March 2021
Participant information sheet (PIS) [pis]	2	20 January 2021
Research protocol or project proposal [Study protocol]	3	17 February 2021
Response to Additional Conditions Met		
Summary CV for Chief Investigator (CI) [CV McCallum]		20 January 2021
Summary CV for student		20 January 2021
Summary CV for supervisor (student research)		01 June 2021

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

IRAS Project ID: 272255	**Please quote this number on all correspondence**

Yours sincerely

Sarah Graves

E-mail: solihull.rec@hra.nhs.uk

West Midlands - Solihull Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

06 June 2022

Dr Marianne McCallum
General Practice and Primary Care
1 Horselethill Road
Glasgow
G12 9LX

Dear Dr Marianne McCallum

Study title:	**Multimorbidity in the context Of Socioeconomic deprivation: An exploration of how Individual and Community factors interact to influence patient capacity to manage Multimorbidity**
REC reference:	**21/WM/0079**
Amendment number:	**AM01 GN20HS047**
Amendment date:	**27 April 2022**
IRAS project ID:	**272255**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment tool]	1	06 December 2021
Research protocol or project proposal [IRAS protocol tracked v4.0]	4	22 March 2022

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities- see details at: https://www.hra.nhs.uk/planning-andimproving-research/learning/

IRAS Project ID - 272255:	**Please quote this number on all correspondence**

Yours sincerely

Dr Rex J Polson Chair

E-mail: solihull.rec@hra.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Dr Marianne McCallum*
West Midlands - Solihull Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 04 May 2022

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Richard Mupanemunda	Consultant Paediatrician	Yes	
Dr Rex J Polson	Consultant Physician	Yes	Meeting Chair

Also in attendance:

Name	*Position (or reason for attending)*
Miss Nabeelah Chothia	Approvals Administrator

Appendix 8 Data Extraction form for Participant Observation

Organisation :	(Underlying organisation, Group/sub-group, Person/people in charge, ?part of something bigger)
Place:	Physical location, community/organisation/hybrid space
Date and time	
Participants	Who is it for? Who has come? Number? Any key characteristics of participants?
Observer	Who is there? Previous interaction with this group?
Planned agenda	Purpose of meeting, what is meant to happen? Agenda (if available) organiser/participants
Overview (who got involved, what happened, how did people engaged)	Summary Key themes: Capacity (enablement, barriers/facilitators, agency) Treatment Burden (work given/reduced) Other key themes
Setting	Physical space, how is used, props (or lack of) does anything change,
Atmosphere	
Extra observations not covered above	

Appendix 9 Topic Guide Interviews

Topic guide - Interviews

What are your long-term conditions?

What medications are you on?(Explore understanding of conditions – what they are and implications)

Who lives with you? What other groups of friends or family do you have nearby?

- Prompt: clarify and explore social networks

Do you know your neighbours?

- Prompt: ask for help, friends?

How long have you lived here? Do you feel part of the community?

What are the best bits about Drumchapel? Are there any negatives?

What sorts of groups are you involved in?

Do you get any other support from the community?

Are you able to get where you want to be in Drumchapel?

How do your LTCs affect your day-to-day life?

What sorts of things do you have to do to manage your conditions?

- Prompts: appointments, medication, lifestyle changes

How do you manage/cope with changes in you condition? E.g., worsening/improving

Who is involved in arranging care and services for someone with all your conditions? Does anyone help you with this? If so, who?

How easy or difficult has it been for you to learn about your health problems or treatments , understand advice from health professionals?

How easy or difficult it is for you to get repeat prescriptions, organise your medications or remember to take them?

How easy or difficult is it for you to make, attend or keep medical or nursing appointments in your practice or at the hospital? Has this changed during the pandemic? If yes, explain….

To what extent do you experience problems with health professionals not communicating well with each other or getting conflicting advice from health professionals?

Have you ever had to get adaptations to your house or aids? If so, how hard or difficult was this to get?

If you've ever applied for benefits or help to manage your chronic health problems, how difficult or easy has this been and can you describe your experiences?

Does trying to manage your conditions impact on what you are and aren't able to do in your everyday life?

Do your health problems impact on your relationships with family and friends?

How do you find out what is available to help you with your different health conditions and how do you get to use the services/get access?

Who do you 'work' with to manage and arrange care and services? (e.g., family, friends, NHS, charities, local groups)

Are there things or people that help or hinder you being able to arrange and access the care and services that you need?

What helps you do the work to manage your conditions?

- Prompts: environmental factors, transport, family friends

What makes that work more difficult?

- Prompts: finance, understanding medication/illness

Are there things or services in Drumchapel that make it easier or harder to manage your conditions?

In your opinion what is missing that would help you better manage your health problems or what do you think is still missing or needed?

For example:

Are there any services or care options that you need that aren't available?

- Is there anything about the way the services are provided/delivered that make them easier/more difficult to access/use?

- Do you have everything you need to be able to arrange care/services

- What resources do you know of to help you with your health conditions and which do you use?

- Are you happy with the way things are working out at the moment in terms of your health?

- Is there anything you would change?

What do you see as the biggest barriers to you managing or coping well with your health problems?

Finally, some people in this work have mentioned they feel Drumchapel is the sort of place people know each other and look out for each other – do you feel that?

Some people have also said they think that people outside the scheme have the wrong idea about what it is like as a place – do you feel that?

- Prompt: negative stories?

Some people have said the relationship with their doctor can impact how they manage their health – have you found that?

- Trust? Continuity? Sharing power? Co-ordination?

Finally thinking of your wider community are there things that you think may be easier about managing your health if you lived somewhere else?

Appendix 10 Asset Based Workshop Outline

Aims:

- To promote discussion and explore participants thoughts regarding their local community and what they feel are key local assets that support their health and wellbeing.
- To start to understand how these local community assets might support, or hinder, them from managing long term conditions.

Structure

- Introduction:
  A 5-minute presentation briefly discussing the aims of the whole project, as well as the aim of this workshop.. Briefly discuss the concepts of assets and the plan to try and develop an asset-based map of the area. We will emphasise this is about finding out what THEY think, so there are no right or wrong answers. In addition, we will briefly discuss ways they may benefit from taking part.
- Icebreaker:
  Ask everyone to get into pairs and introduce themselves with some scripted easy to answer questions that should not feel threatening (e.g. name, a hobby, favourite tv show)Then each person introduces the other to the wider group. The idea behind this is to break down awkwardness and barriers, aiming for easy to answer but slightly humorous questions. 15(mins)
- Initial exercise:
  Individual exercise using the circles of connectivity (using the model from the IRISS co-production project planner kit): as well as several blank copies for participants there will be one (?two) already filled in as an example, using words and pictures. There will the option to draw rather than write if people prefer. After 10 minutes on own ask people to share with their neighbour – explain we expect this is likely to make them think of other things and they can add them to their circles for 15 minutes. This will be followed by 25 minutes group feedback (try and arrange on flip chart by assets of individuals, assets of associations/groups, assets of organisations, physical assets, economic assets and cultural assets).(Foot, 2010) Leave up these charts for the rest of the day and encourage people to add to them throughout the workshop (50 mins).
- Break for refreshments (30 minutes)
- Creative mapping exercise:
  Split into 2-3 groups depending on size of group, give each an A0 piece of paper and ask them to “draw” Drumchapel. This doesn’t need to be accurate; we will suggest putting in the main roads, community landmarks, recreational areas, shops, supermarkets etc – what is important to them. We will then offer different materials which they can use as they wish to create their own map of assets (lego, pens, post-its, play dough), listing intangible assets if they come up (30 minutes).
- Group discussion
  Starting with feedback from each group (as well as their assets, how did they feel the activity went, did they enjoy it, what was important? Were there any surprises?).
- Feedback from my time in Drumchapel, focusing on assets itself (discussing concepts of safe space/challenge/power of peer/authenticity, and shared community experience of nothing working for you and shared stigma).
- Facilitated discussion using topic guide below (40 minutes)
- Summary exercise

Use post it notes to write on and stick on assets, and why, onto large map of Drumchapel, also if possible, create flip chart of list of key characteristics that make assets an important source of support (15mins).

Topic Guide for facilitated discussion

How do you feel the activity went? What did you enjoy? Have you thought about the community in this way before?

After our recent activities what do your think are important assets in Drumchapel?

- Do any surprise you?

I am going to go back through the key findings from my recent work and would be grateful to hear your thoughts?

In terms of community groups does it matter to you if they are authentic? Why?

How important was ease of access in accessing [group]?

Do you recognise the idea of safe space in [group]? If so what things help this feel like a safe space? Are there other examples where this has or has not been this case.

Do you think having peers in the group, people with lived experience, makes a difference?

- Why do you think that?
- Are there other examples where you have experienced this?

Have you experienced being challenged in [group].

- Was it effective?
- Why? Why not?

I found that people from Drumchapel often feel they are judged by people not living in the community – do you experience that? Can you give examples?

I also found people experienced none of the systems working for them? Do you recognise that? Can you give examples?

Are there times when the health service has not worked for you? Are there times when it really has?

What is your experience with your GP practice?
What are the important qualities in your GP and their team?

- Prompts (access vs continuity, is trust important)

We have discussed a lot, we've looked at the assets and strengths in the community, and some of the problems. What do you think would be the next steps to improve health in Drumchapel?

Could the assets you've identified by used better?

Are there any other things that are not in the community now that might be of benefit?
Is there anything that has not been brought up that you think is important?

Appendix 11 Topic Guide Focus Group

Welcome

Outline group rules

I am going to go back through the key findings from my recent work and would be grateful to hear your thoughts?

Presentation Key Findings

I found that people from Drumchapel often feel they are judged by people not living in the community – do you experience that? Can you give examples?

I also found people experienced none of the systems working for them? Do you recognise that? Can you give examples?

Are there times when the health service has not worked for you? Are there times when it really has?

What is your experience with your GP practice?
What are the important qualities in your GP and their team?

- Prompts (access vs continuity, is trust important)

We have discussed a lot, we've looked at the assets and strengths in the community, and some of the problems. What do you think would be the next steps to improve health in Drumchapel?

Are there any other things that are not in the community now that might be of benefit?
Is there anything that has not been brought up that you think is important?

Appendix 12: Patterns of missingness across the West of Scotland 20-07 Data Set

This appendix provides more detail on the patterns of missingness between the waves, across all four models. Each model's section contains two sets of tables. The first demonstrates what variables were collected at each wave, and for whom. The second table demonstrates the numbers for each variable, and the numbers and percentage missing at each wave. The tables are followed by three figures which provide a visual representation of missingness across the dataset. The first highlights the pattern of missingness by variable for each wave. The second and third figure demonstrates the pattern of missingness across variables. The figures allow exploration of the specific patterns of missingness, and particularly highlight the complex issues with between wave missingness, particularly at wave 3.

Mobilising capacity

Table A1 - Table demonstrating whether mobilising capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at baseline

Wave 1						
	1930L	1930R	1950L	1950L	1970L	1970R
Income	■	■	■	■	■	■
Car Ownership	■	■	■	■	■	■
Housing tenancy	■	■	■	■	■	■
Employment status	■	■	■	■	■	■
Family contacts	■	■	■	■	■	■
Friend contacts	■	■	■	■	■	■
Share Feelings	■	■				
Someone to confide in	■	■				
Practical Support						
Loneliness	■	■				
Carer	■	■				
Divorce	■	■				
Change Employment	■	■				
Unemployment	■	■			■	■
Death in family	■	■			■	■
Death Friend	■	■				

Table A2 - Table demonstrating whether mobilising capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at Wave 2

Wave 2						
	1930L	1930R	1950L	1950L	1970L	1970R
Income	■	■	■	■	■	■
Car Ownership	■	■	■	■	■	■
Housing tenancy	■	■	■	■	■	■
Employment type	■	■	■	■		
Family contacts	■	■	■	■	■	■
Friend contacts	■	■	■	■	■	■
Share Feelings	■	■	■	■		
Someone to confide in	■	■	■	■		
Practical Support	■	■	■	■		
Loneliness	■	■	■	■		
Carer	■	■	■	■		
Divorce	■	■	■	■	■	■
Change Employment						
Unemployment						
Death in Family	■	■	■	■	■	■
Death Friend	■	■	■	■	■	■

Table A3 - Table demonstrating whether mobilising capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at Wave 3

Wave 3						
Income	■	■	■	■	■	■
Car Ownership	■	■	■	■	■	■
Housing tenancy	■	■	■	■	■	■
Employment type	■	■	■	■	■	■
Family contacts	■	■	■	■	■	■
Friend contacts	■	■	■	■	■	■
Share Feelings		■		■		■
Someone to confide in		■		■		■
Practical Support		■		■		■
Carer		■		■		■
Loneliness	■	■	■	■	■	■
Divorce	■	■	■	■	■	■
Change Employment		■		■		■
Unemployment		■		■		■
Death in family		■		■		■
Death friend		■		■		■

Table A4 - Table demonstrating whether mobilising capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at Waves 4 and 5

Waves and 5						
Income	■	■	■	■	■	■
Car Ownership	■	■	■	■	■	■
Housing tenancy	■	■	■	■	■	■
Employment type	■	■	■	■	■	■
Family contacts	■	■	■	■	■	■
Friend contacts	■	■	■	■	■	■
Share Feelings	■	■	■	■	■	■
Someone to confide in	■	■	■	■	■	■
Practical Support	■	■	■	■	■	■
Carer	■	■	■	■	■	■
Loneliness	■	■	■	■	■	■
Divorce	■	■	■	■	■	■
Change Employment	■	■	■	■	■	■
Unemployment	■	■	■	■	■	■
Death in family	■	■	■	■	■	■

Table A5 – Table demonstrating the numbers collected and numbers, and percentages, missing for mobilising capacity variables at Wave 1

Variable	Number	Missing (n)	Missing (%)
Income	2064	185	8.2
Car Ownership	2237	12	0.5
Housing tenancy	2237	12	0.5
Employment status	2227	12	1
Family contacts	1126	1123	49.9
Friend contacts	391	1859	82.7
Share Feelings	1104	1145	50.9
Someone to confide in	1124	1125	50.0
Practical Support	N/A	3613	80.1
Carer	1126	1123	49.9
Loneliness	1126	1123	65.6
Divorce	1126	1123	49.9
Change employment	1126	1123	49.9
Unemployment	1126	1123	49.9
Death family	1458	791	35.2
Death Friend	1507	742	33.0

Table A6– Table demonstrating the numbers collected and numbers, and percentage, missing for mobilising capacity variables at Wave 2

Variable	Number	Missing (n)	Missing (%)
Income	1936	313	13.9
Car Ownership	2054	195	8.7
Housing tenancy	2051	198	9.8
Employment status	2027	222	9.9
Family contacts	2022	227	10.1
Friend contacts	566	1683	74.8
Share Feelings	1663	586	26.1
Someone to confide in	1677	572	25.4
Practical Support	1653	596	26.5
Carer	2055	194	8.6
Loneliness	1677	572	25.4
Divorce	2076	173	7.7
Change employment	N/A		
Unemployment	N/A		
Death family	N/A		
Death Friend	N/A		

Table A7– Table demonstrating the numbers collected and numbers, and percentage, missing for mobilising capacity variables at Wave 3

Variable	Number	Missing (n)	Missing (%)
Income	1468	781	34.7
Car Ownership	1683	566	25.2
Housing tenancy	1717	532	23.7
Employment status	1664	585	26
Family contacts	1167	1982	48.1
Friend contacts	1094	1155	51.4
Share Feelings	1239	1010	44.9
Someone to confide in	1250	999	44.4
Practical Support	1226	1023	45.5
Carer	1249	1000	44.5
Loneliness	1798	541	24.1
Divorce	1377	872	38.8
Change employment	1386	863	38.4
Unemployment	841	1408	62.6
Death family	1058	1191	53
Death Friend	1173	1076	47.8

Table A8– Table demonstrating the numbers collected and numbers, and percentage, missing for mobilising capacity variables at Wave 4

Variable	Number	Missing (n)	Missing (%)
Income	130	945	42
Car Ownership	1552	697	31
Housing tenancy	1553	696	30.9
Employment status	1534	715	31.8
Family contacts	1554	695	30.9
Friend contacts	1553	696	30.9
Share Feelings	1528	721	32.1
Someone to confide in	1547	702	31.2
Practical Support	1519	730	32.5
Carer	1553	696	30.9
Loneliness	1552	697	31
Divorce	1557	692	30.8
Change employment	1264	985	43.8
Unemployment	1264	985	43.8
Death family	1264	985	43.8
Death Friend	1264	985	43.8

Table A9– Table demonstrating the numbers collected and numbers, and percentage, missing for mobilising capacity variables at Wave 5

Variable	Number	Missing (n)	Missing (%)
Income	1263	986	43.8
Car Ownership	1452	797	35.4
Housing tenancy	1486	763	33.9
Employment status	1456	793	35.3
Family contacts	1484	765	34
Friend contacts	1484	765	34
Share Feelings	1452	797	35.4
Someone to confide in	1465	789	34.7
Practical Support	1465	784	34.9
Carer	1453	796	35.4
Loneliness	1470	779	34.6
Divorce	1493	756	33.6
Change employment	1452	797	35.4
Unemployment	1452	797	35.4
Death family	1492	757	33.7
Death Friend	1451	798	35.5

Figure A1: Figure demonstrating missingness for each mobilising capacity variable across the cohort at baseline.

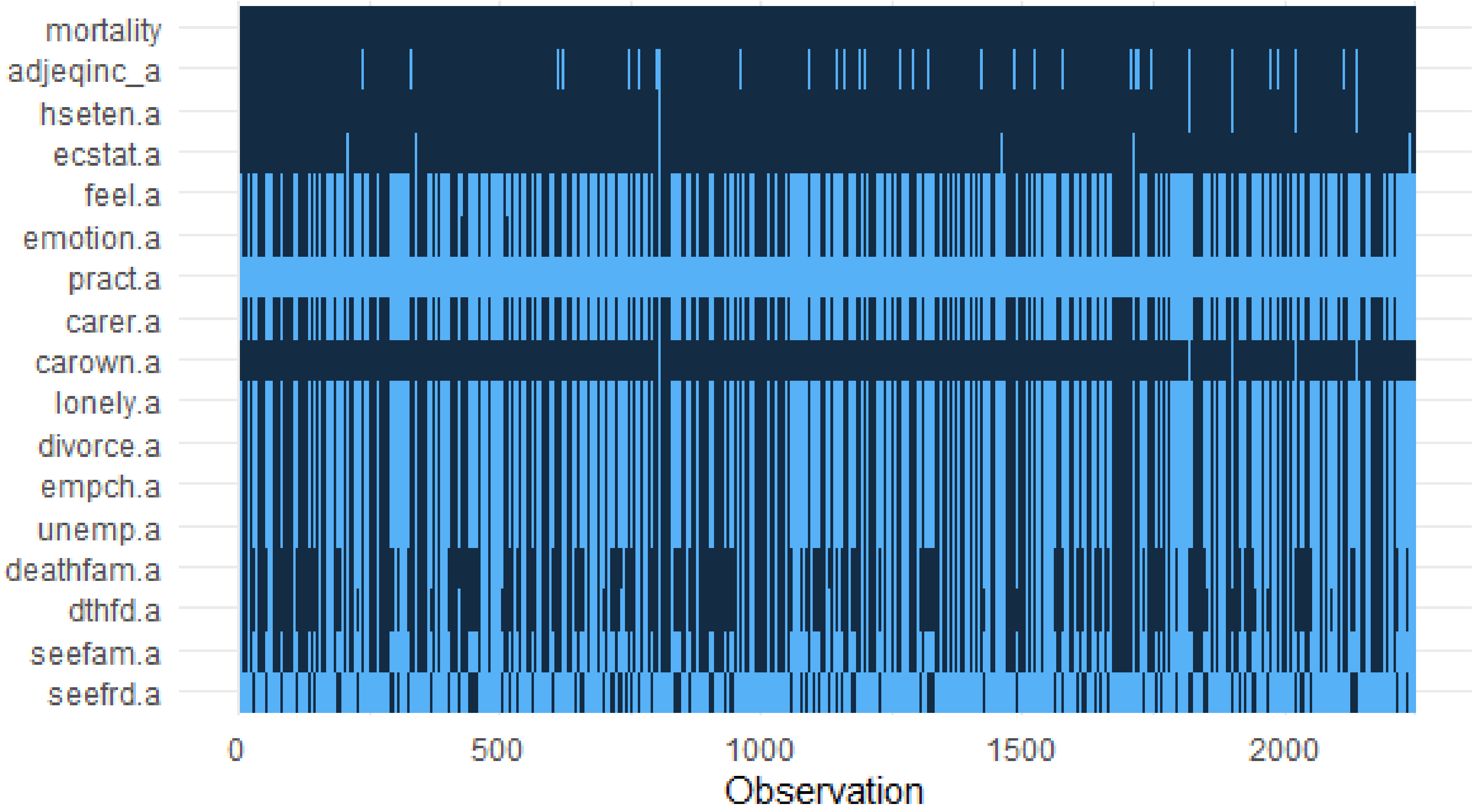
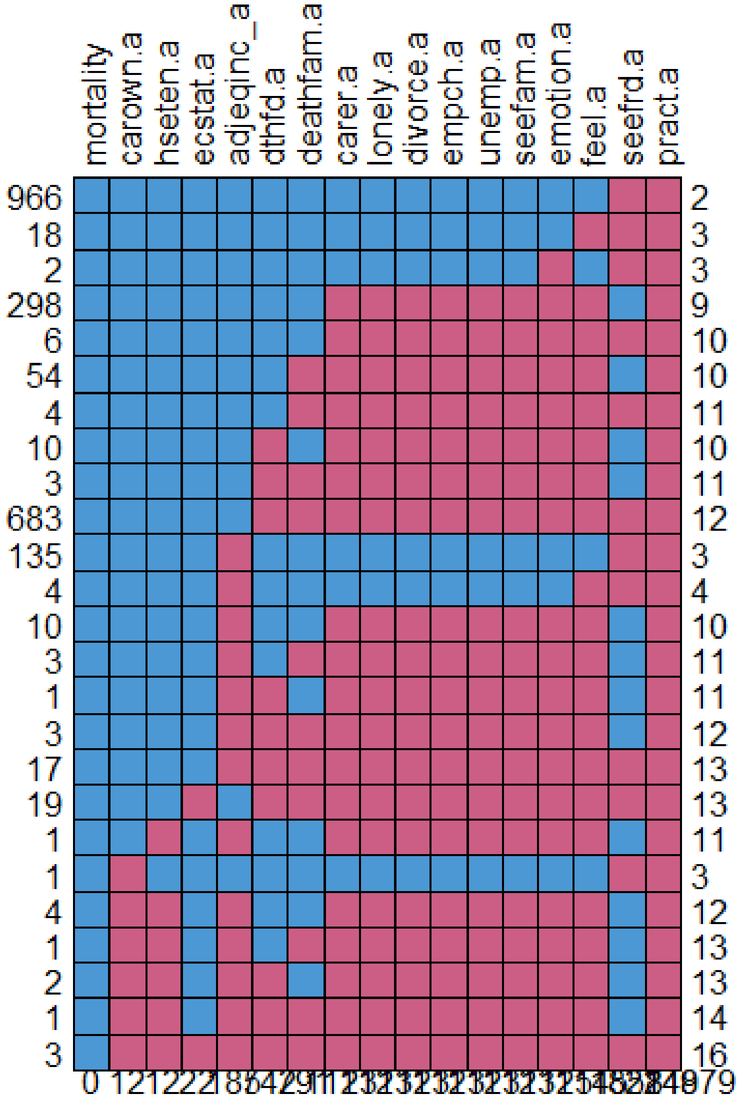


Figure A2: Figure demonstrating missingness pattern between mobilising capacity variable at baseline



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966	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟥	🟥	2
18	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟥	🟥	🟥	3
2	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟥	🟦	🟥	🟥	3
298	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟦	🟥	9
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Figure A3 Graph demonstrating the numbers of people missing specific combinations of mobilising capacity variables across the cohort at baseline.

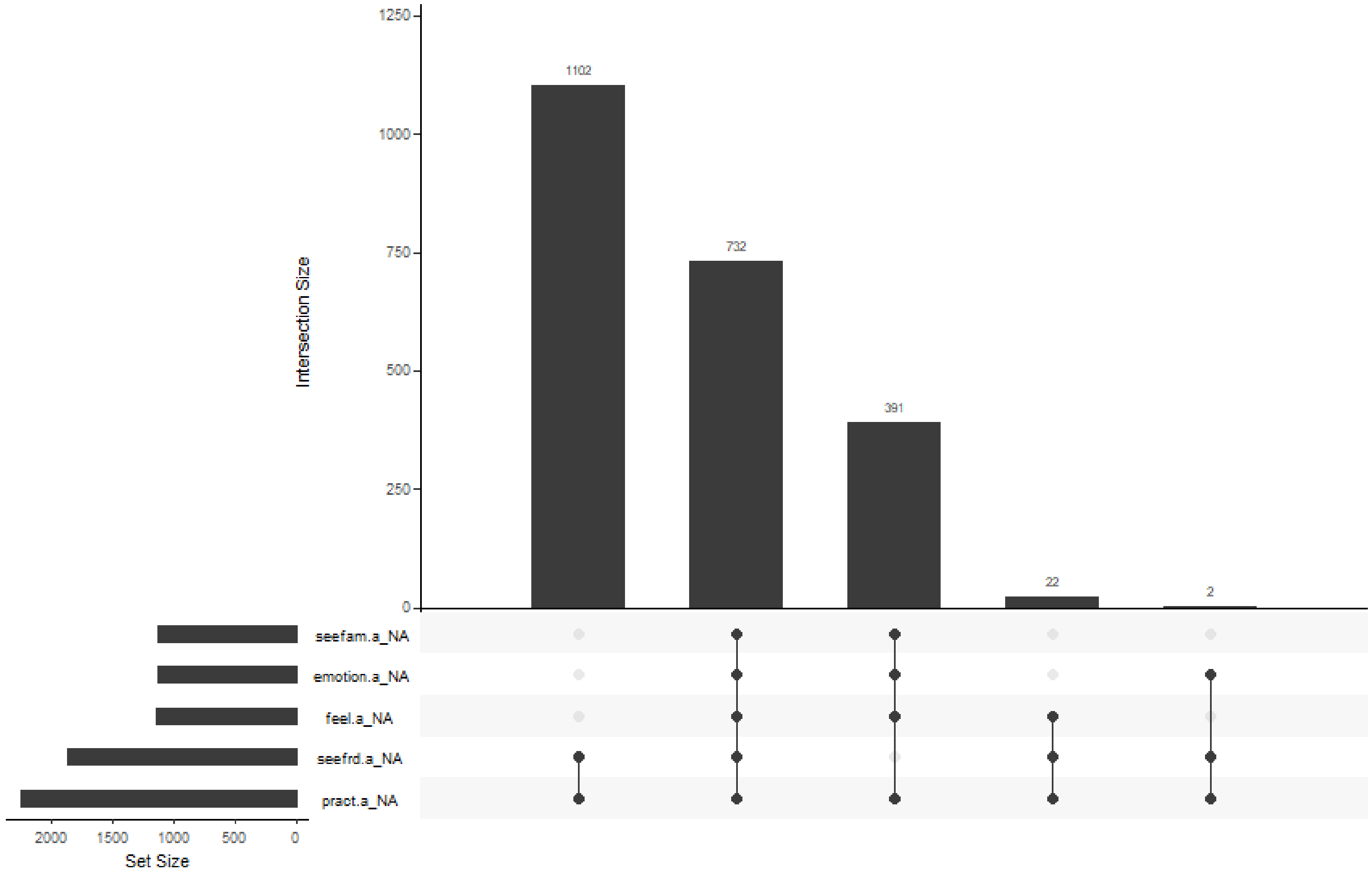


Figure A4: Figure demonstrating missingness for each mobilising capacity variables across the cohort at wave 2.

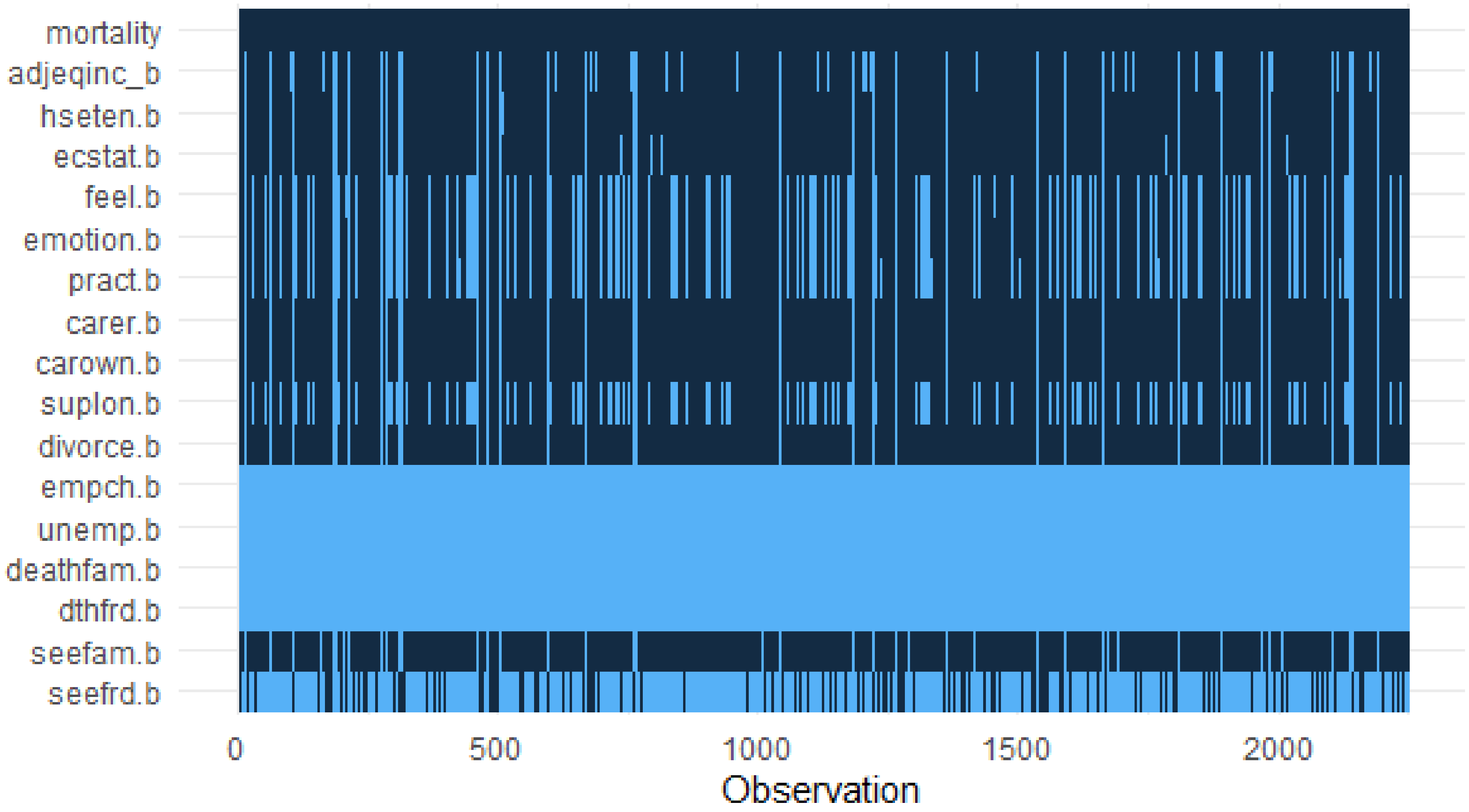


Figure A5: Figure demonstrating missingness pattern between mobilising capacity variables at wave 2

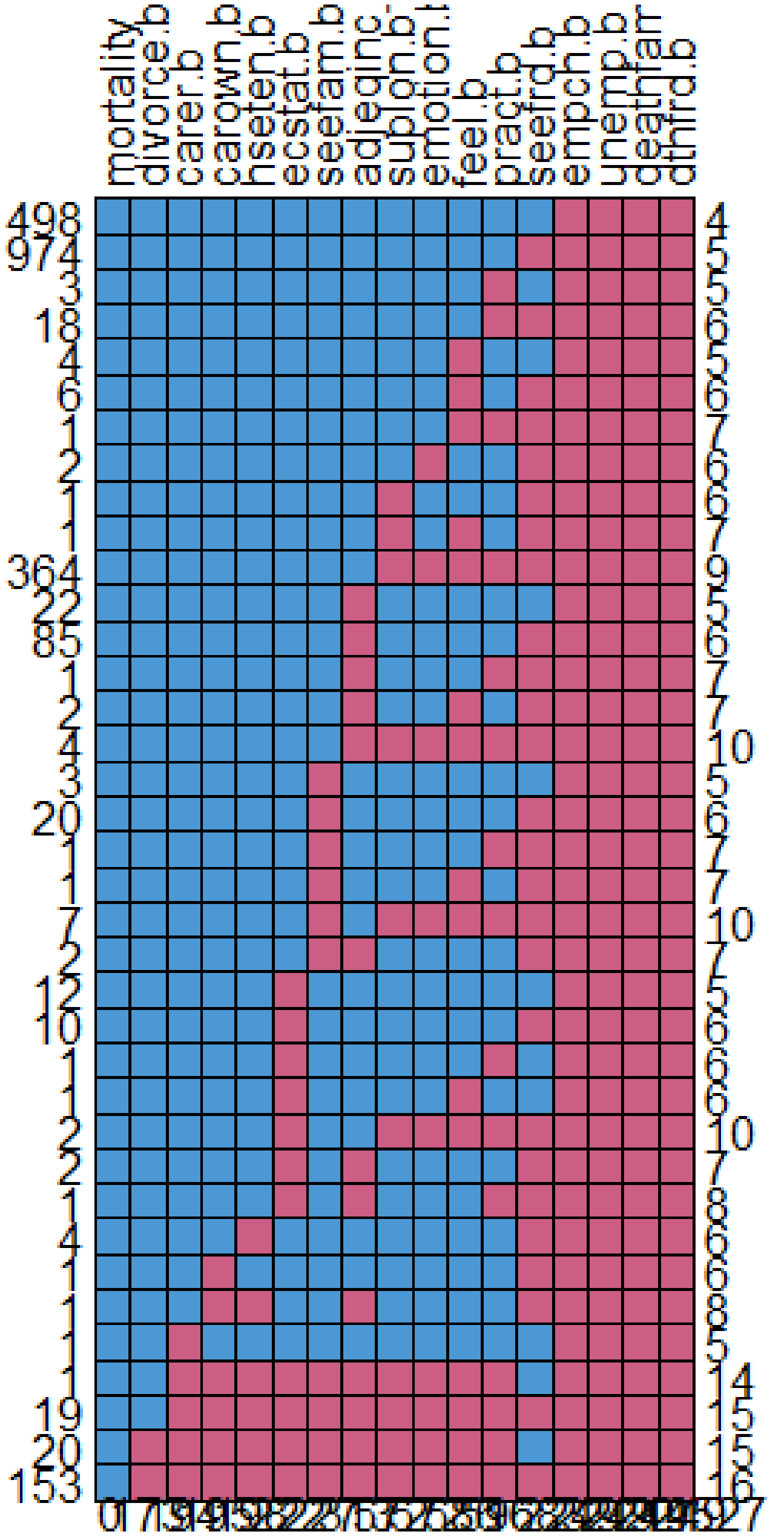


Figure A6 Graph demonstrating the numbers of people missing specific combinations of mobilising capacity variables across the cohort at Wave 2

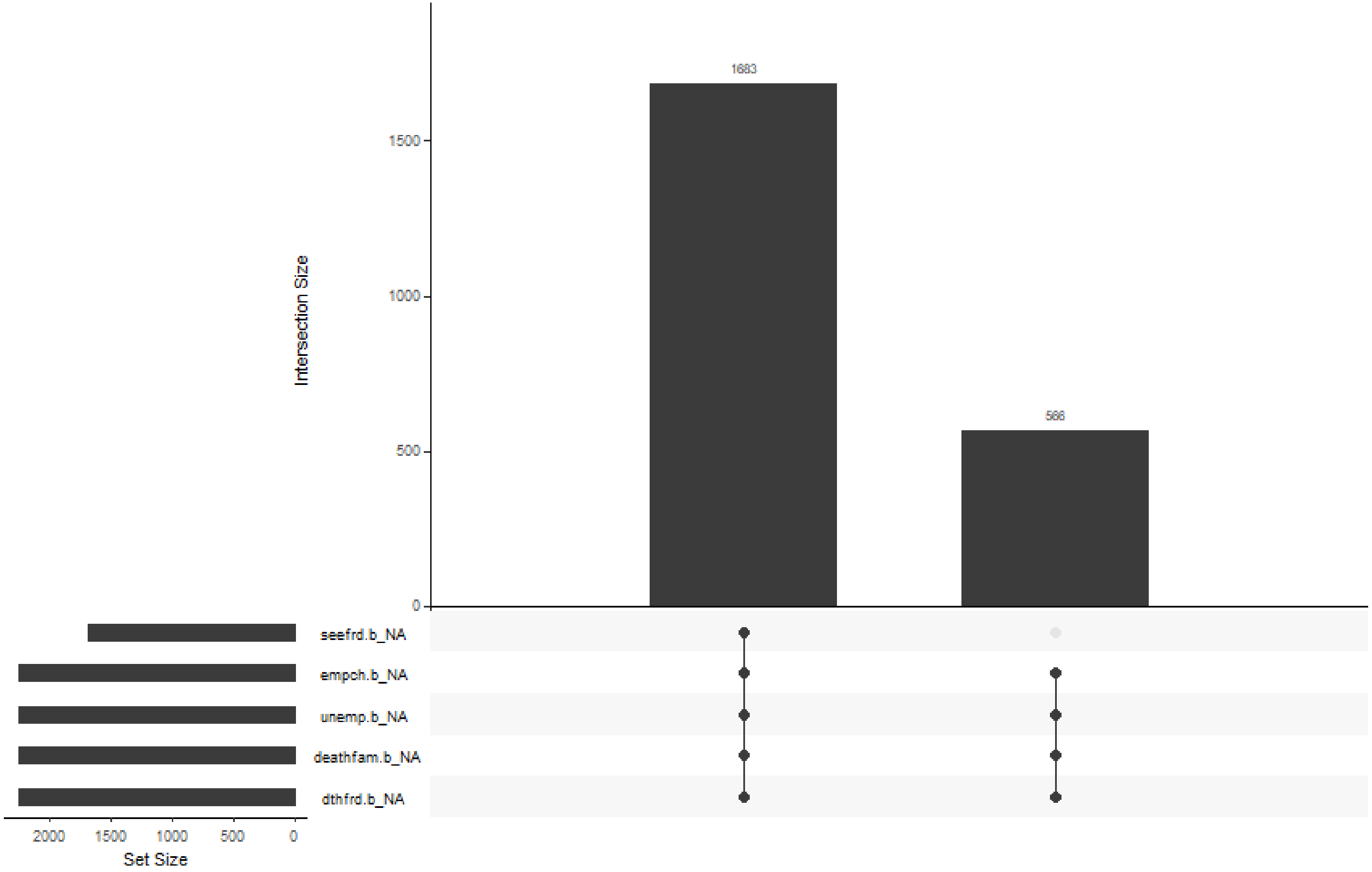


Figure A7 Figure demonstrating missingness for each mobilising capacity variable across the cohort at wave 3.

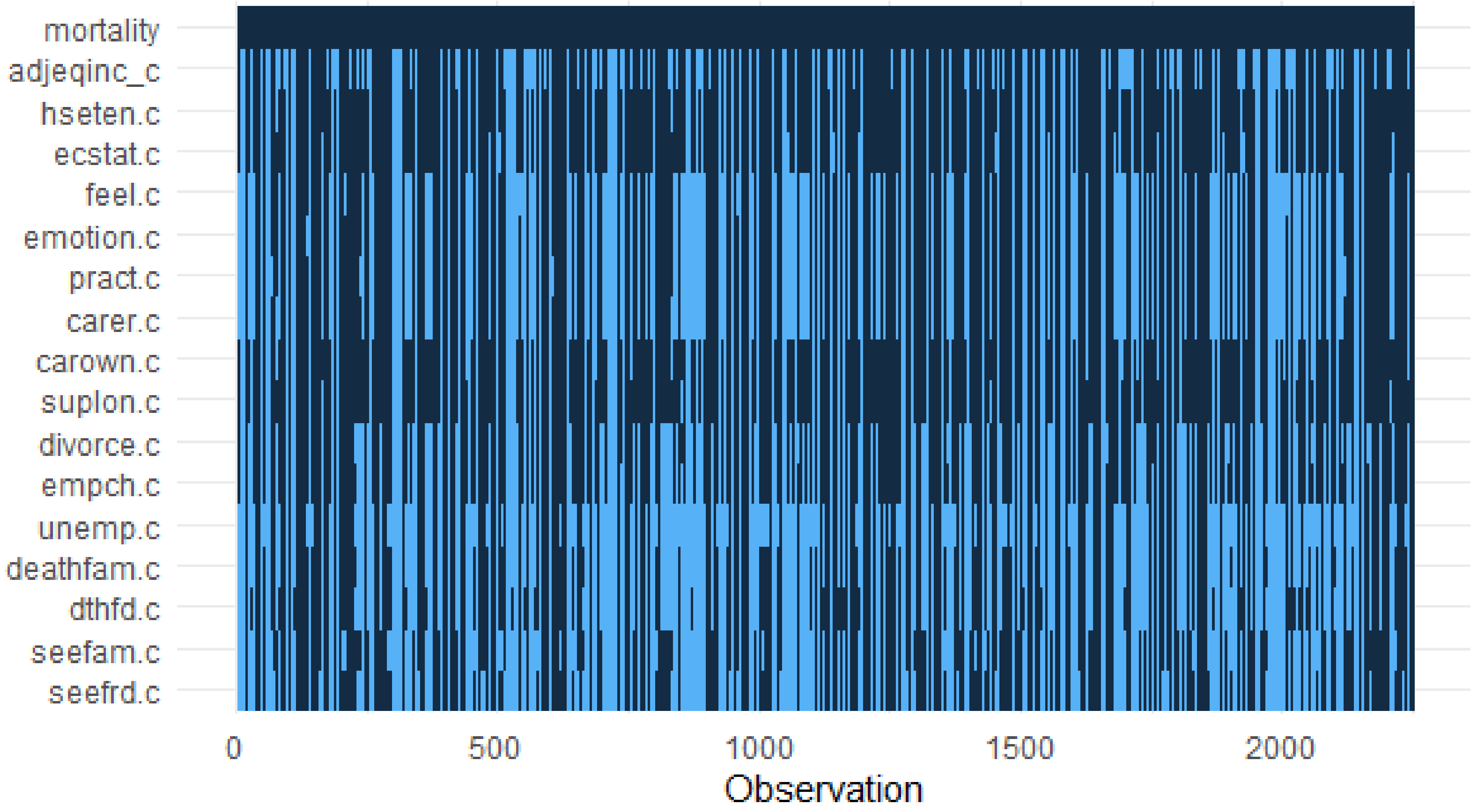


Figure A8: Figure demonstrating missingness pattern between mobilising capacity variable at wave 3 (due to the complex patterns of missingness this figure is particualrly difficult to interpret)

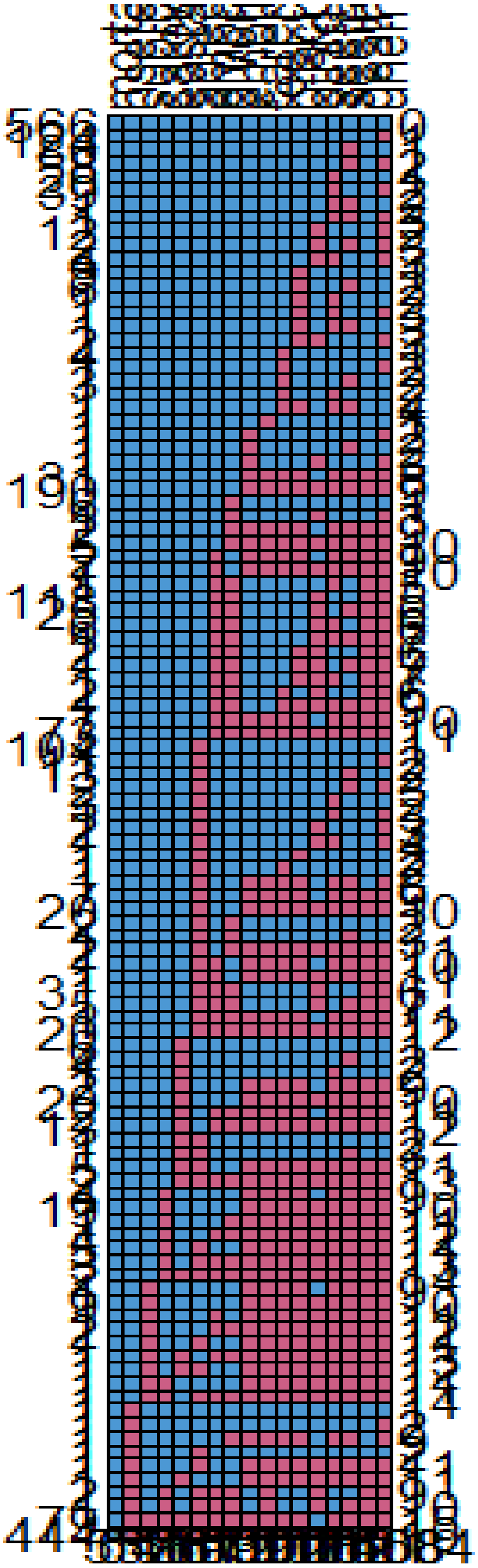


Figure A9 Graph demonstrating the numbers of people missing specific combinations of mobilising capacity variables across the cohort at wave 3.

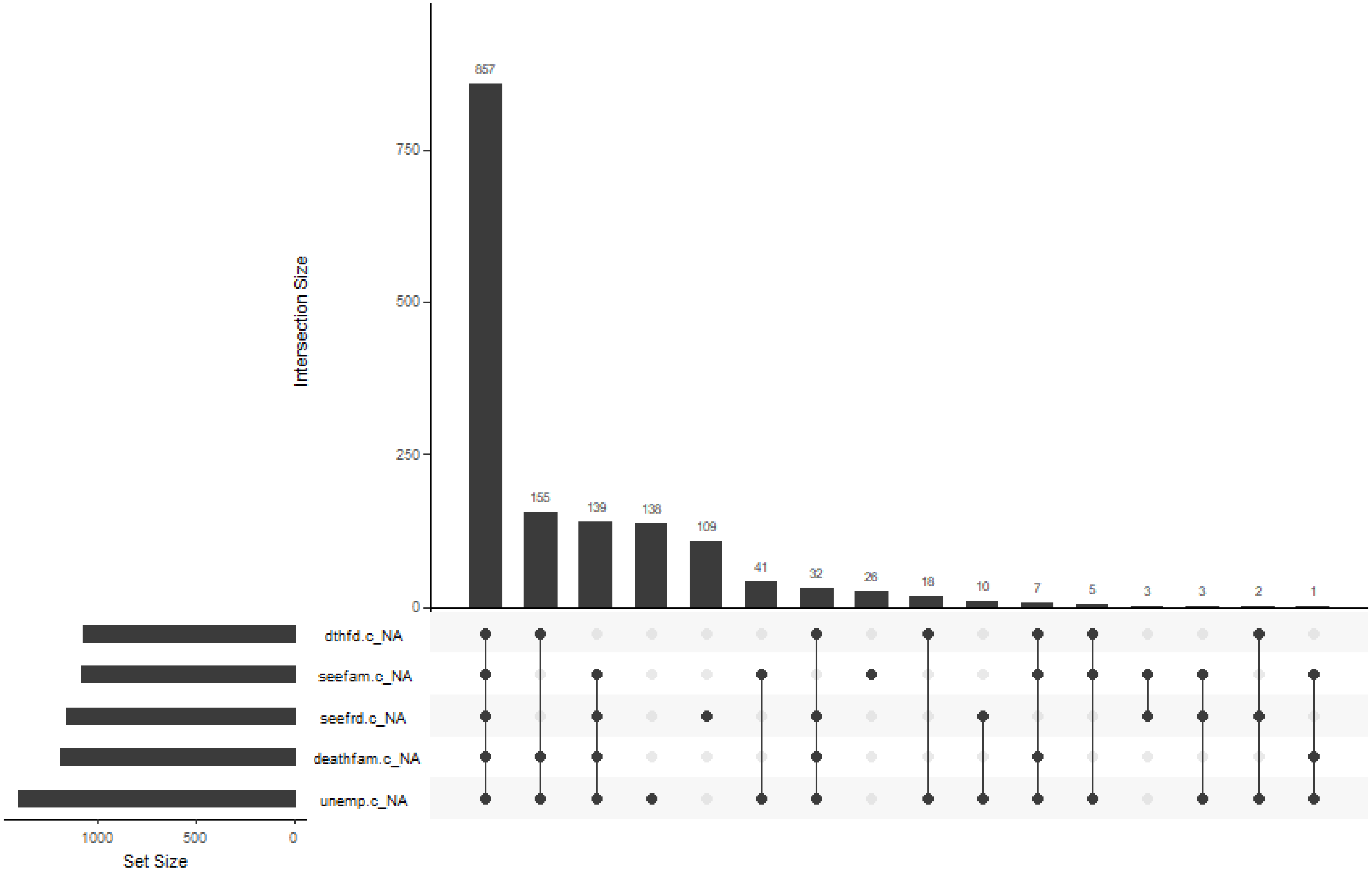


Figure A10: Figure demonstrating missingness for each mobilising capacity variable across the cohort at Wave 4.

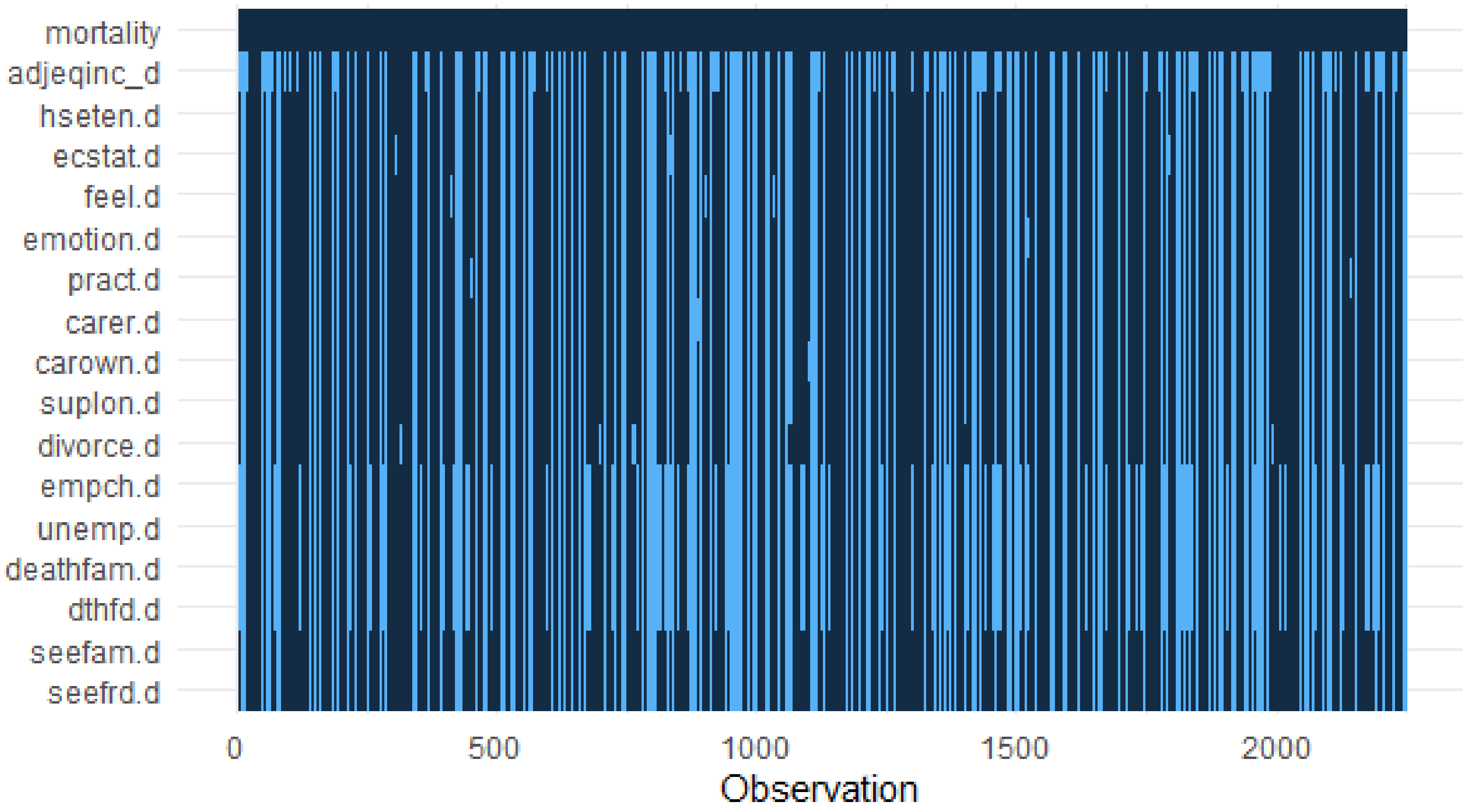


Figure A11: Figure demonstrating missingness pattern between mobilising capacity variables at wave 4

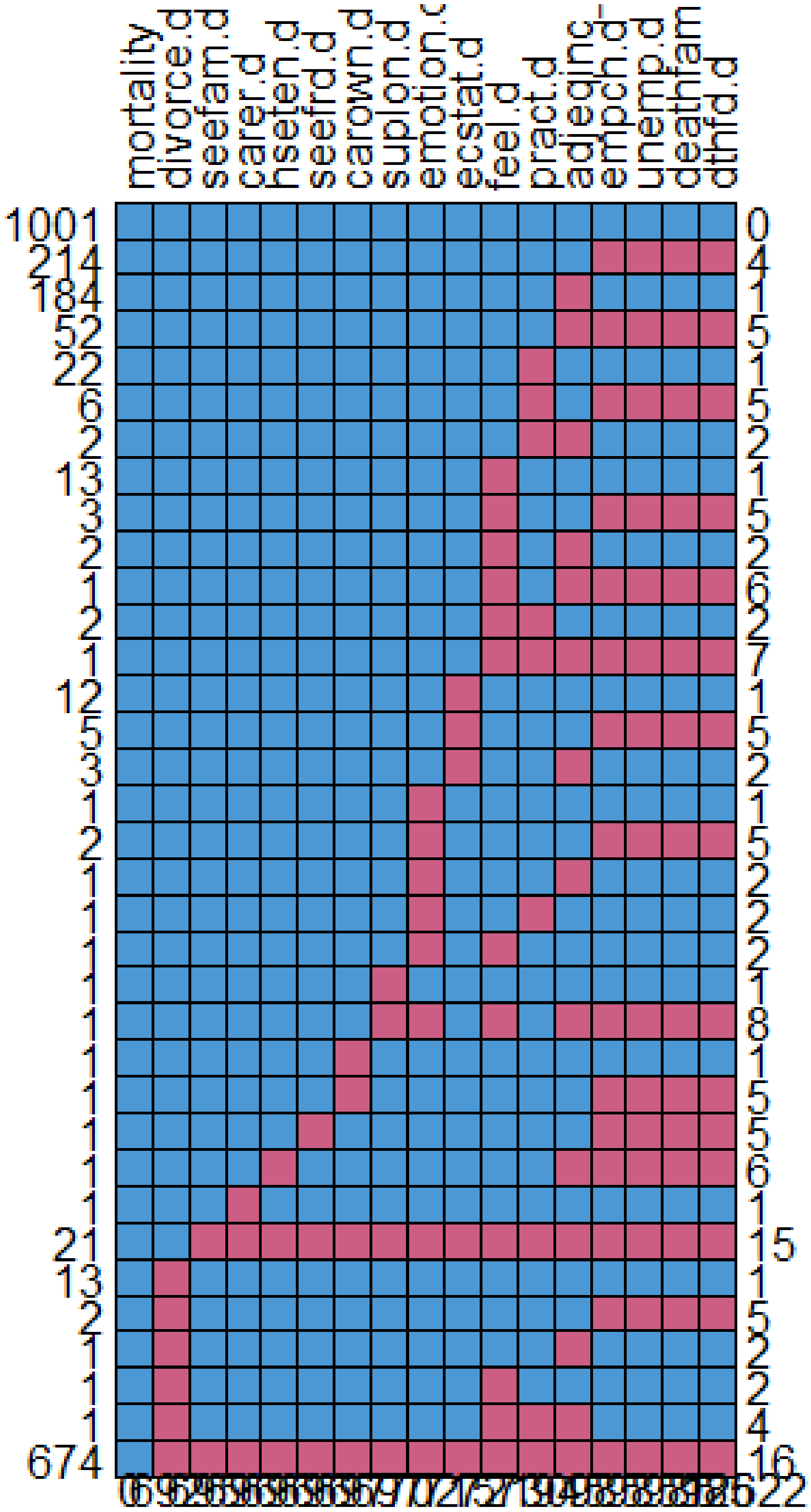


Figure A12 Graph demonstrating the numbers of people missing specific combinations of mobilising capacity variables across the cohort at wave 4.

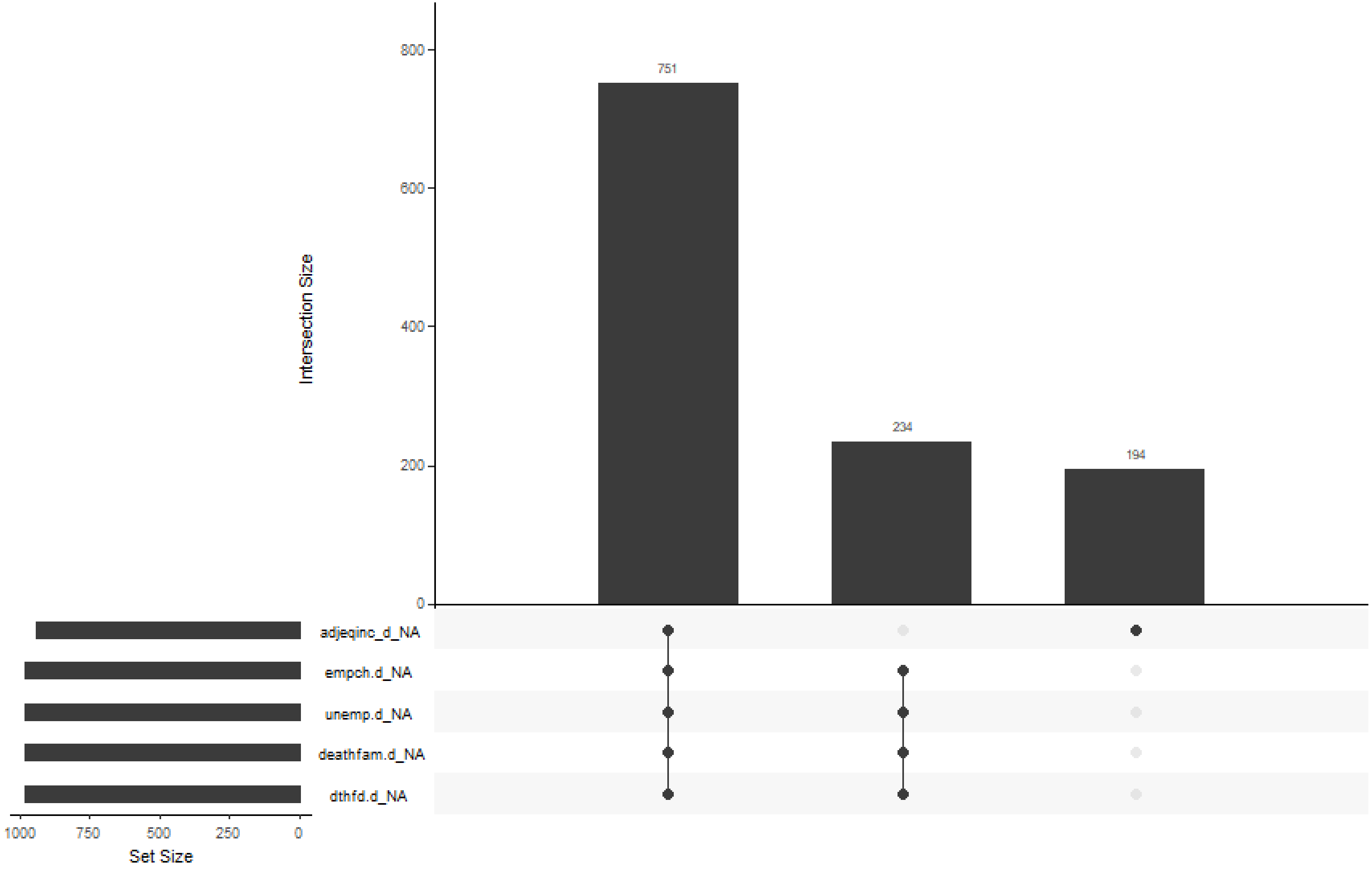


Figure A13: Figure demonstrating missingness for each mobilising capacity variable across the cohort at wave five.

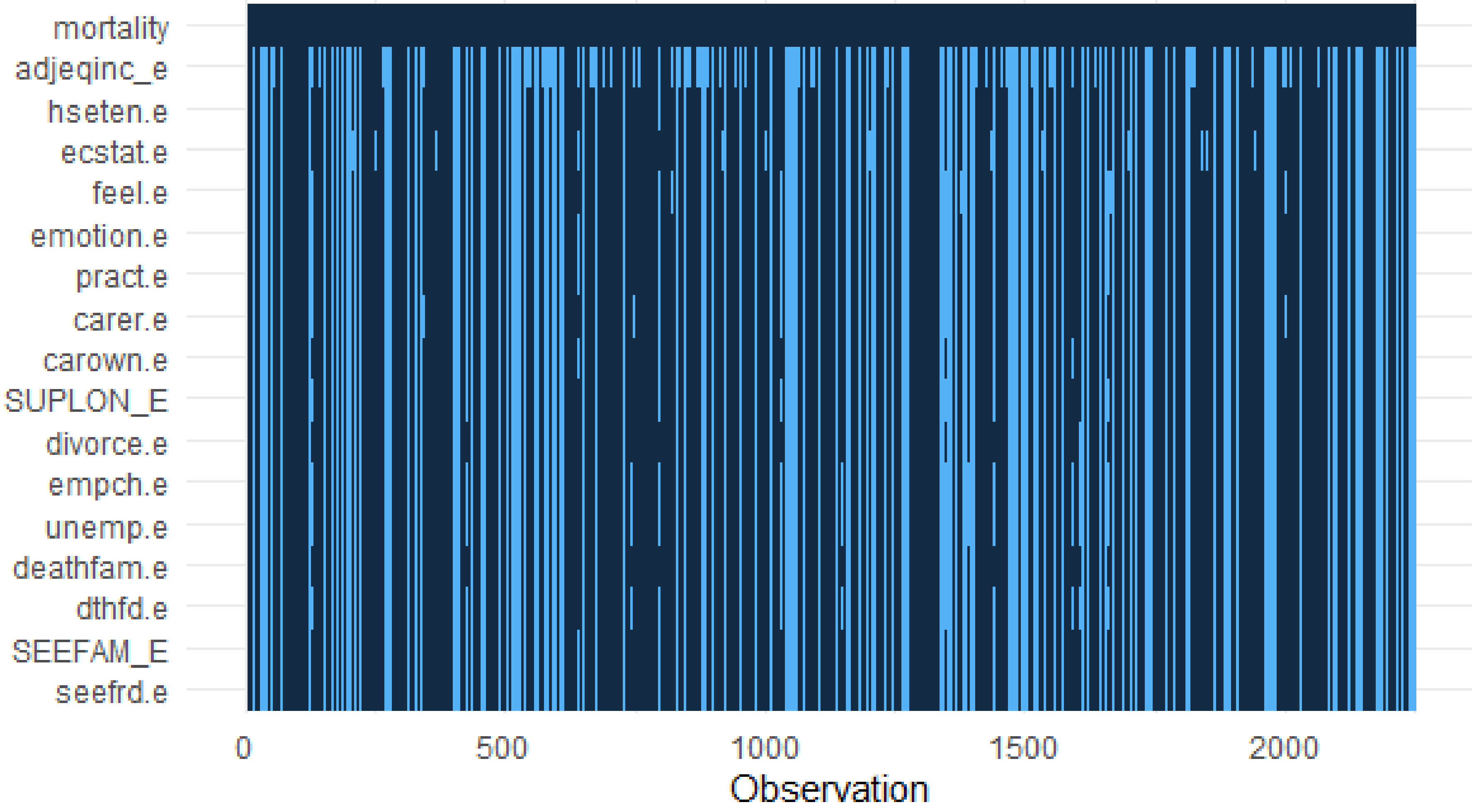


Figure A14: Figure demonstrating missingness pattern between mobilising capacity variables at wave 5

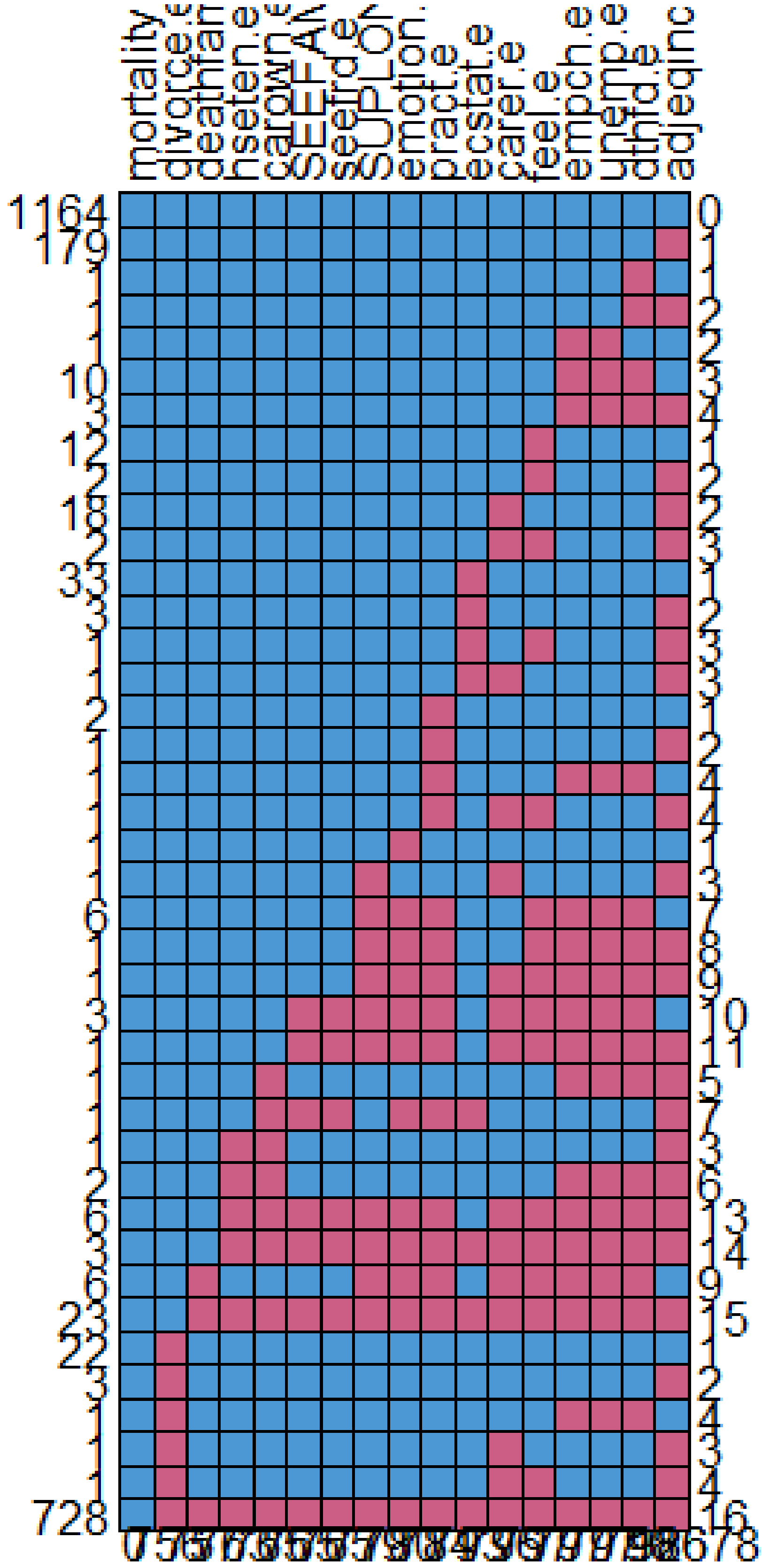
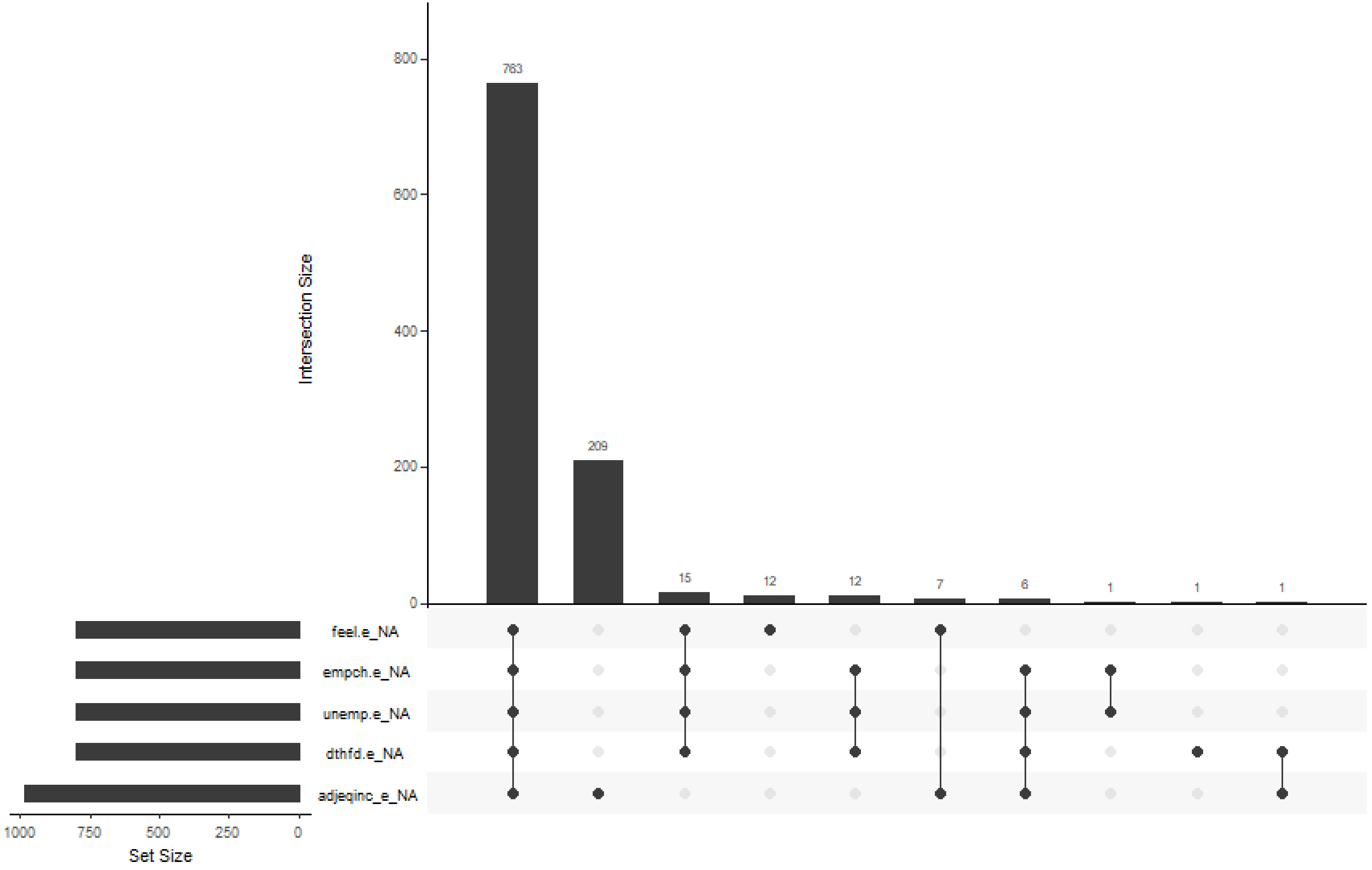


Figure A15 Graph demonstrating the numbers of people missing specific combinations of mobilising capacity variables across the cohort at wave 5.



Expressing Capacity

Table A10- Table demonstrating whether expressing capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at baseline

Wave 1						
	1930L	1930R	1950L	1950L	1970L	1970R
Health in last year	■	■	■	■	■	■
Health for age	■	■				
Disability						
Life limiting LTC	■	■	■	■	■	■
Depression	■	■				
Anxiety	■	■				
Educational attainment	■	■	■	■	■	■
AH4	■	■				
Self Esteem						
community groups	■	■				
Health locus of control						
Mastery						

Table A11- Table demonstrating whether expressing capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at wave 2.

Wave 2						
	1930L	1930R	1950L	1950L	1970L	1970R
Health in last year	■	■	■	■	■	■
Health for age	■	■	■	■		
Disability	■	■	■	■	■	■
Life limiting LTC	■	■	■	■	■	■
Depression	■	■	■	■	■	■
Anxiety	■	■	■	■	■	■
Educational attainment	■	■	■	■	■	■
AH4						
Self Esteem	■	■	■	■		
community groups	■	■	■	■		
Health locus of control	■	■	■	■	■	■
Mastery						

Table A12- Table demonstrating whether expressing capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at wave 3

Wave 3						
	1930L	1930R	1950L	1950L	1970L	1970R
Health in last year	■	■	■	■	■	■
Health for age		■		■		■
Disability	■	■	■	■	■	■
Life limiting LTC	■	■	■	■	■	■
Depression		■		■		■
Anxiety		■		■		■
Educational attainment	■	■	■	■	■	■
AH4						
Self Esteem		■		■		■
community groups		■		■		■
Health locus of control						
Mastery						

Table A13- Table demonstrating whether expressing capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at wave 4

Wave 4						
	1930L	1930R	1950L	1950L	1970L	1970R
Health in last year	■	■	■	■	■	■
Health for age	■	■	■	■	■	■
Disability	■	■	■	■	■	■
Life limiting LTC	■	■	■	■	■	■
Depression	■	■	■	■	■	■
Anxiety	■	■	■	■	■	■
Educational attainment	■	■	■	■	■	■
AH4	■	■	■	■	■	■
Self Esteem	■	■	■	■	■	■
community groups	■	■	■	■	■	■
Health locus of control						
Mastery	■	■	■	■	■	■

Table A14- Table demonstrating whether expressing capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at wave 5.

Wave 5						
	1930L	1930R	1950L	1950L	1970L	1970R
Health in last year	■	■	■	■	■	■
Health for age	■	■	■	■	■	■
Disability	■	■	■	■	■	■
Life limiting LTC	■	■	■	■	■	■
Depression	■	■	■	■	■	■
Anxiety	■	■	■	■	■	■
Educational attainment	■	■	■	■	■	■
AH4	■	■	■	■	■	■
Self Esteem						
community groups	■	■	■	■	■	■
Health locus of control						
Mastery						

Table A15 – Table demonstrating the numbers for expressing capacity variables collected and numbers, and percentages, missing at Wave 1

Variable	Number	Missing (n)	Missing (%)
Health in last year	2054	195	8.7
Health for age	1673	576	25.6
Disability	Not asked		
Life limiting LTC	2249	0	0
Depression	1085	1164	51.6
Anxiety	1065	1164	52.8
Educational attainment	2248	1	0.0004
AH4	1032	1217	54.1
Self Esteem	Not asked		
Number community groups	1032	1217	54.1
Health locus of control	Not asked		
Mastery	Not asked		

Table A16– Table demonstrating the numbers for expressing capacity variables collected and numbers, and percentages, missing at Wave 2

Variable	Number	Missing (n)	Missing (%)
Health in last year	2226	23	1
Health for age	1106	1143	50.8
Disability	2047	202	9
Life limiting LTC	2057	192	8.5
Depression	2023	226	10
Anxiety	2035	214	9.5
Educational attainment	2248	1	0.0004
AH4	Not asked	1217	54.1
Self Esteem	1651	598	26.6
Number community groups	1677	572	25.4
Health locus of control	1652	597	26.5
Mastery	Not asked		

Table A17– Table demonstrating the numbers for expressing capacity variables collected and numbers, and percentages, missing at Wave 3

Variable	Number	Missing (n)	Missing (%)
Health in last year	1725	524	23.3
Health for age	1252	997	44.3
Disability	1705	544	31.6
Life limiting LTC	1727	522	23.2
Depression	1227	1022	45.4
Anxiety	1231	1018	45.3
Educational attainment	2248	1	0.0004
AH4	Not asked		
Self Esteem	1224	1025	45.6
Number community groups			44.4
Health locus of control	Not asked		
Mastery	Not asked		

Table A18– Table demonstrating the numbers for expressing capacity variables collected and numbers, and percentages, missing at Wave 4

Variable	Number	Missing (n)	Missing (%)
Health in last year	1556	693	30.8
Health for age	1554	695	30.9
Disability	1550	1699	31.1
Life limiting LTC	1557	692	30.8
Depression	1501	748	33.3
Anxiety	1504	745	33.1
Educational attainment	2248	1	0.0004
AH4	1338	911	40.5
Self Esteem	1497	752	33.4
Number community groups	1554	695	30.9
Health locus of control	Not asked		
Mastery	1495	754	33.5

Table A19– Table demonstrating the numbers for expressing capacity variables collected and numbers, and percentages, missing at Wave 5

Variable	Number	Missing (n)	Missing (%)
Health in last year	1493	756	33.6
Health for age	1476	773	34.4
Disability	1487	762	40.8
Life limiting LTC	1498	751	33.4
Depression	1466	783	34.8
Anxiety	1466	783	34.8
Educational attainment	2248	1	0.0004
AH4	1331	918	40.8
Self Esteem	Not Asked		
Number community groups	1464	785	34.9
Health locus of control	Not asked		
Mastery	Not asked		

Figure A16: Figure demonstrating missingness for each expressing capacity variables across the cohort at baseline.

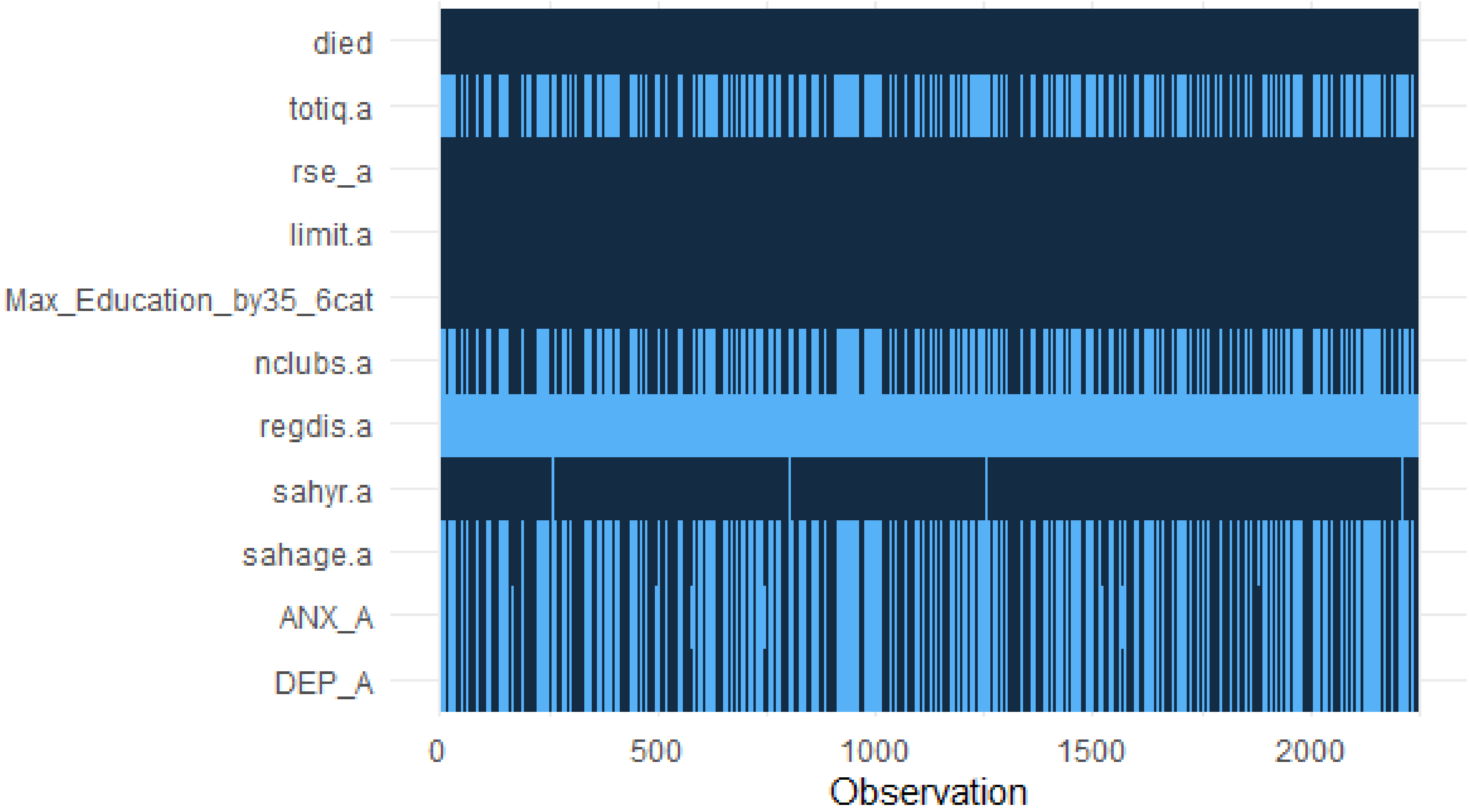


Figure A17: Figure demonstrating missingness pattern between variablesfor the expressing factors at baseline

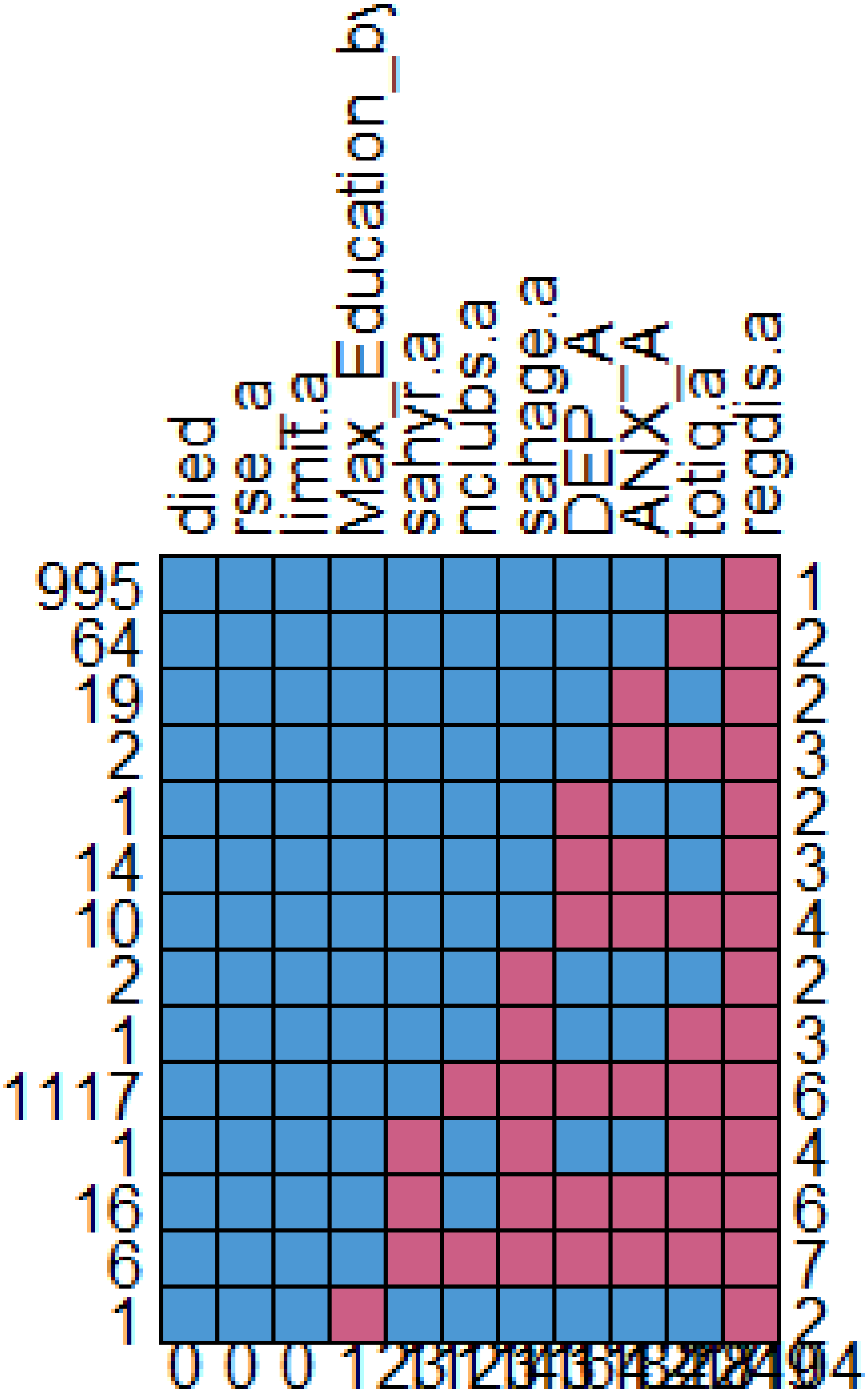


Figure A18 Graph demonstrating the numbers of people missing specific combinations expressing capacity variables across the cohort at baseline

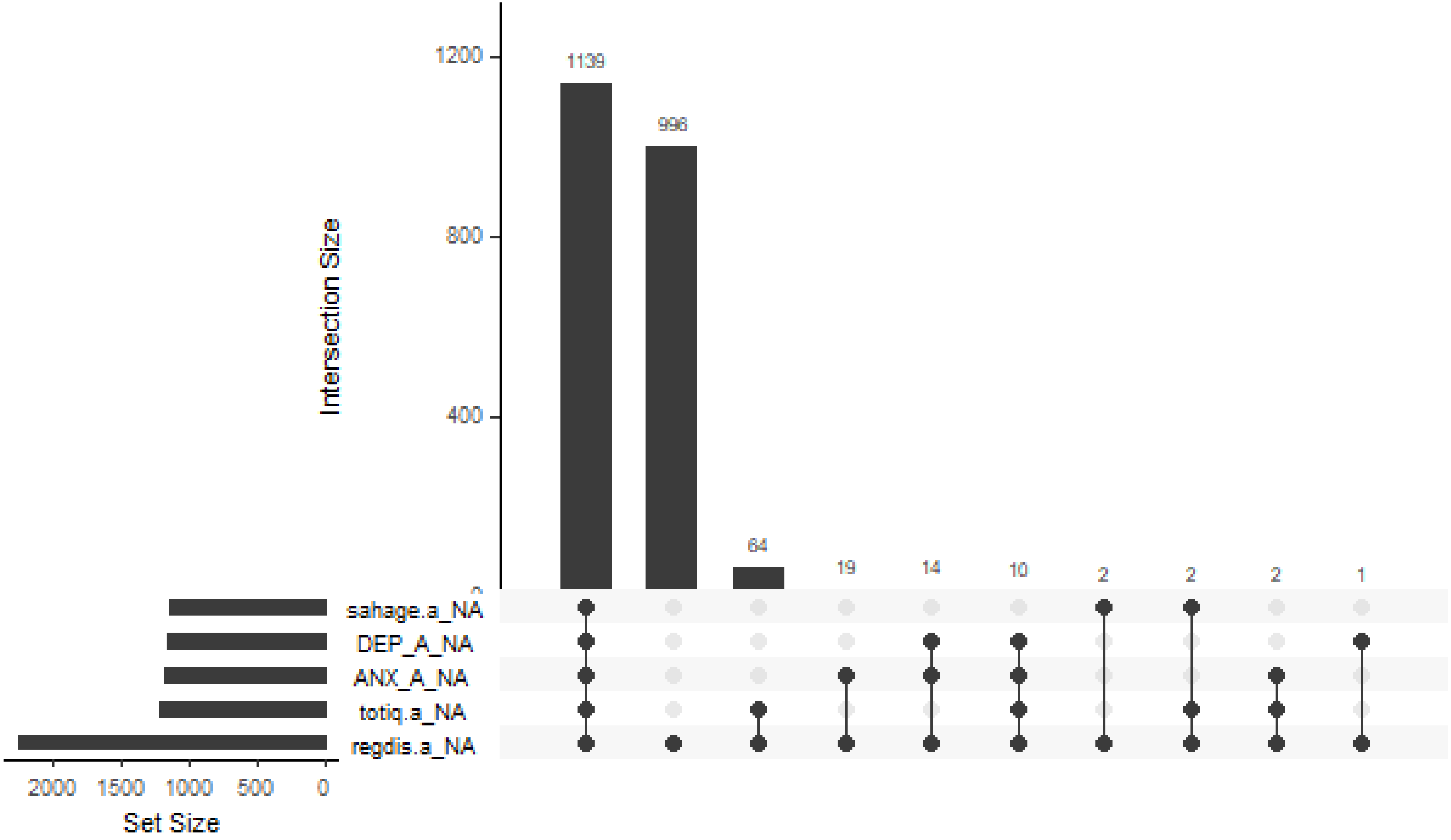


Figure A19: Figure demonstrating missingness for each expressing capacity variable across the cohort at wave 2.

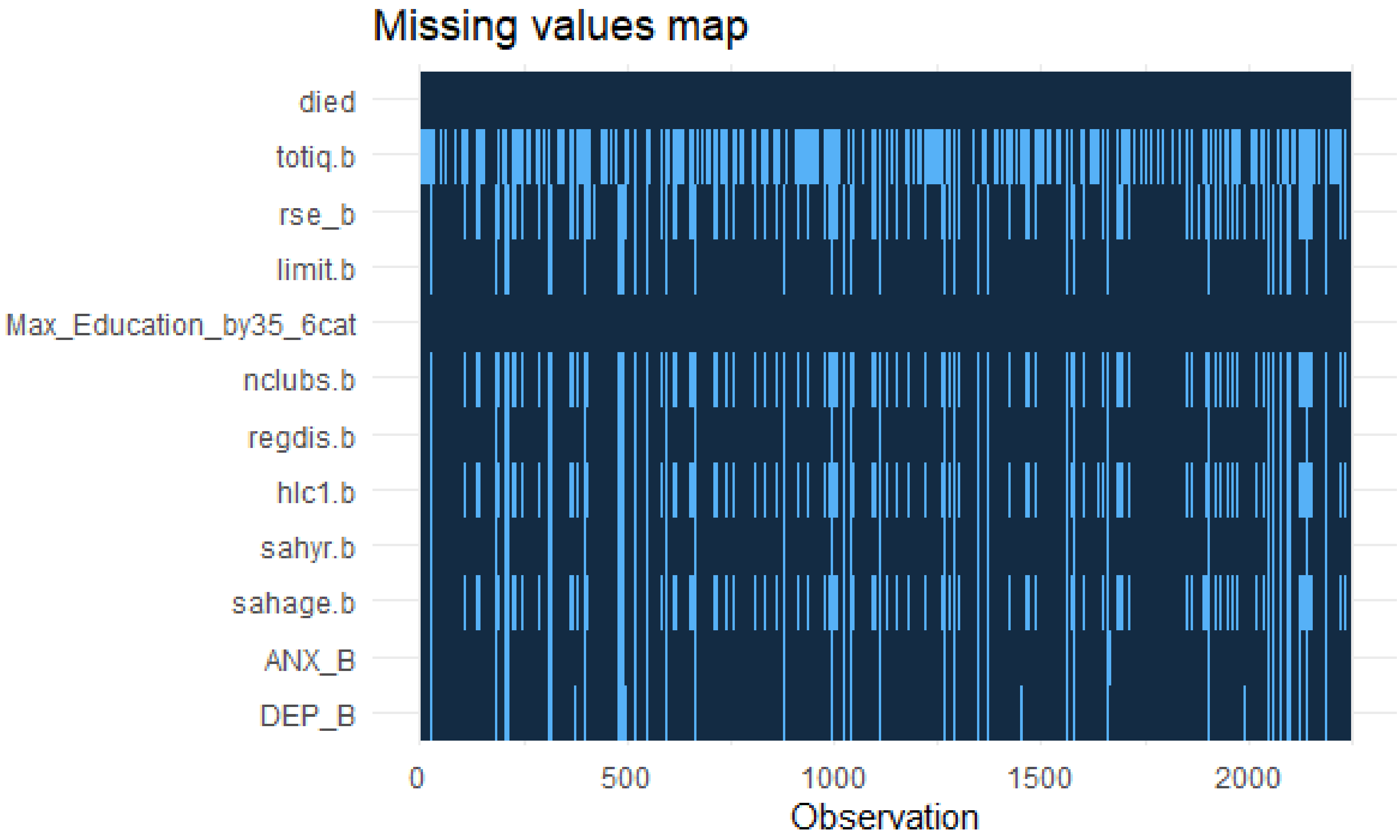


Figure A20: Figure demonstrating missingness pattern between variablesfor the expressing factors at wave 2

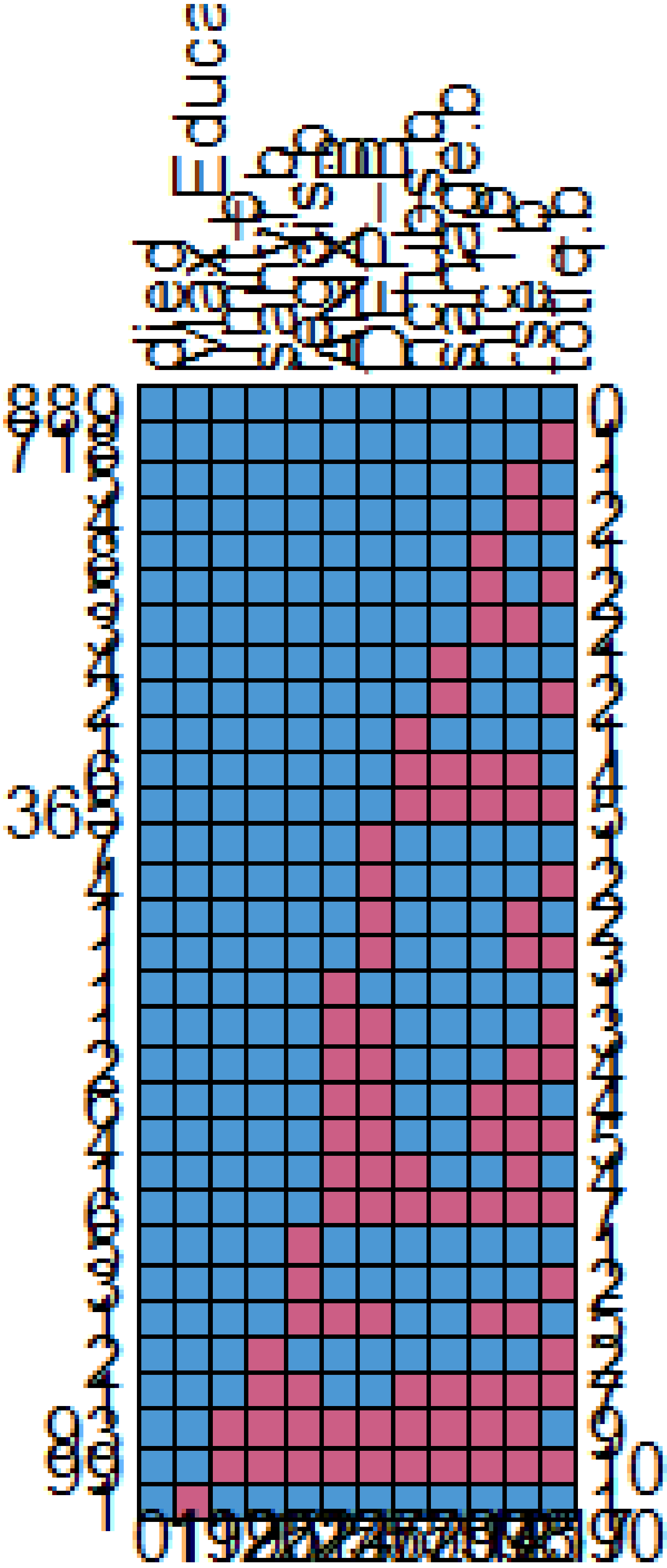


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Figure A21: Figure demonstrating missingness for each expressing capacity variable across the cohort at wave two.

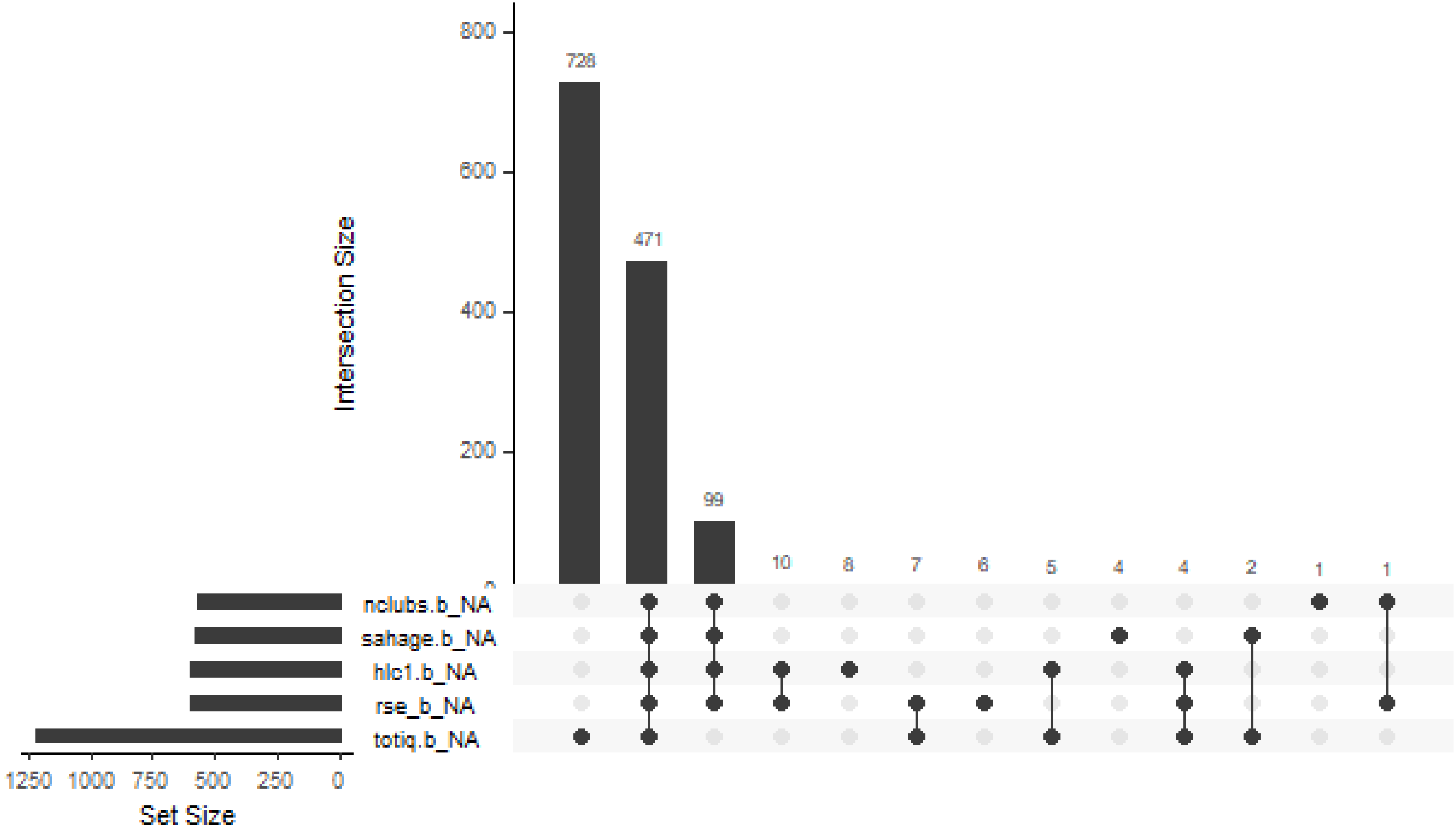

Figure A22: Figure demonstrating missingness for each expressing capacity variable across the cohort at wave three.

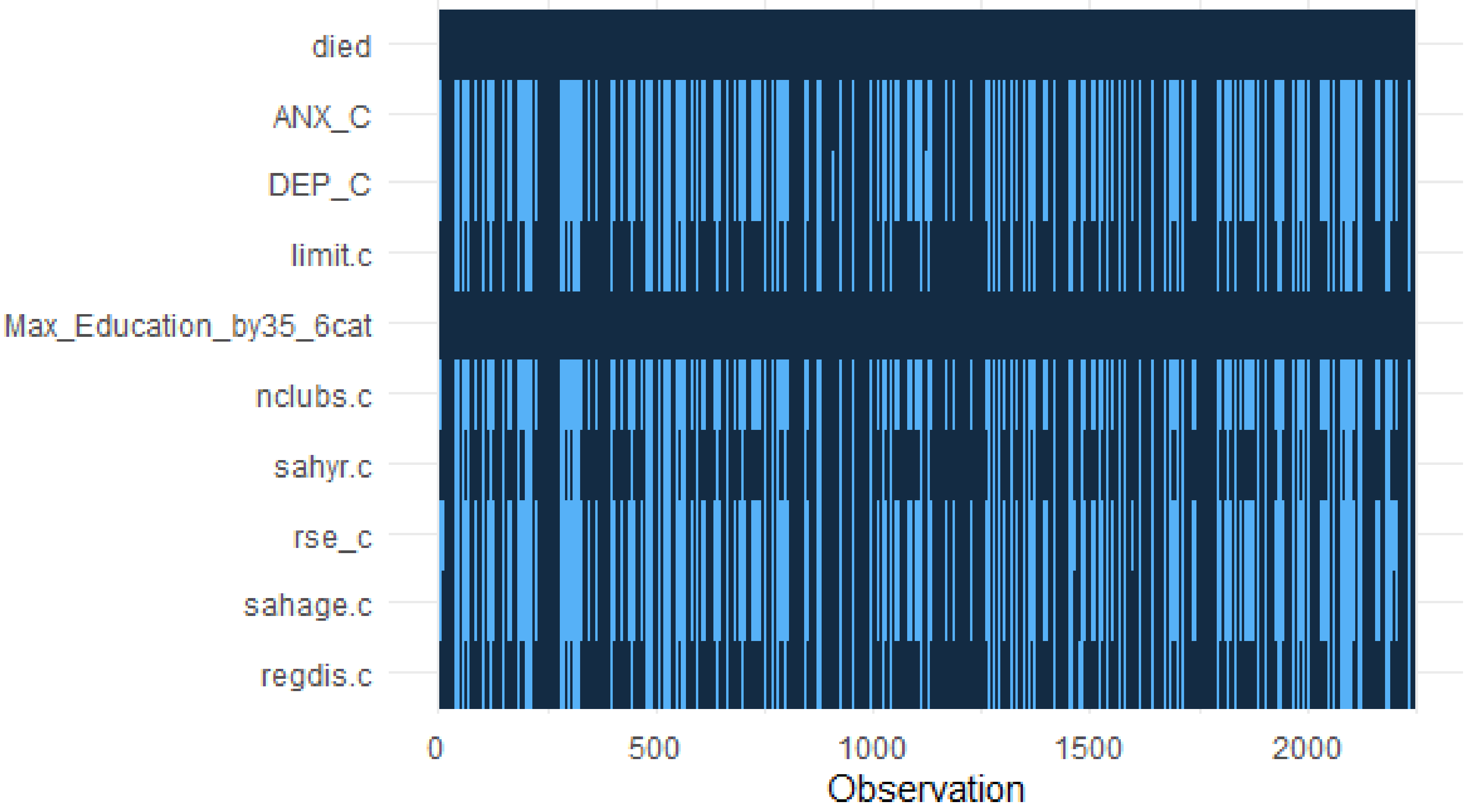

Figure A23: Figure demonstrating missingness pattern between variables for the expressing factors at wave 2

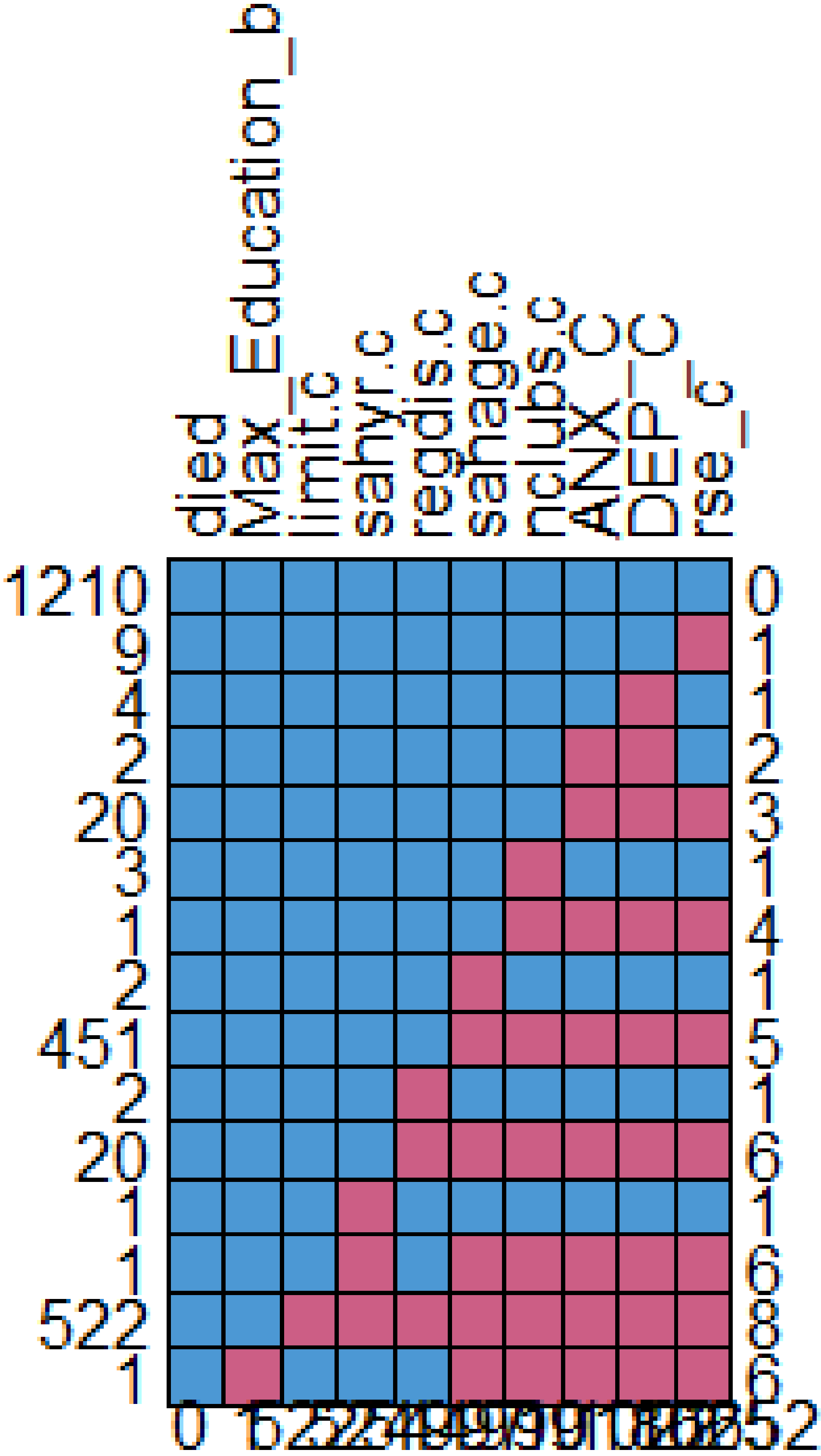

Figure A24: Figure demonstrating missingness for each expressing capacity variable across the cohort at wave three

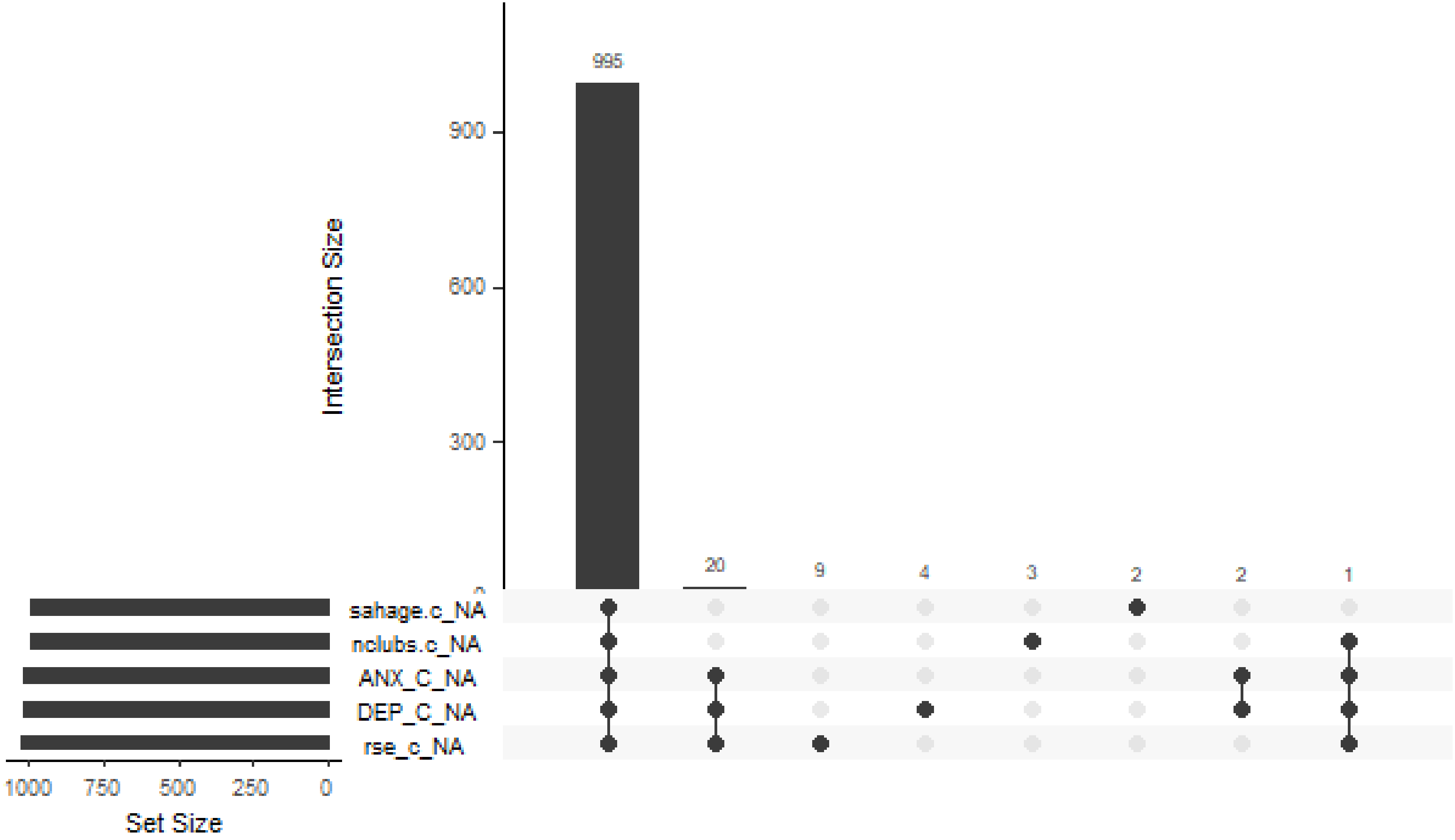

Figure A25: Figure demonstrating missingness for each expressing capacity variable across the cohort at wave four

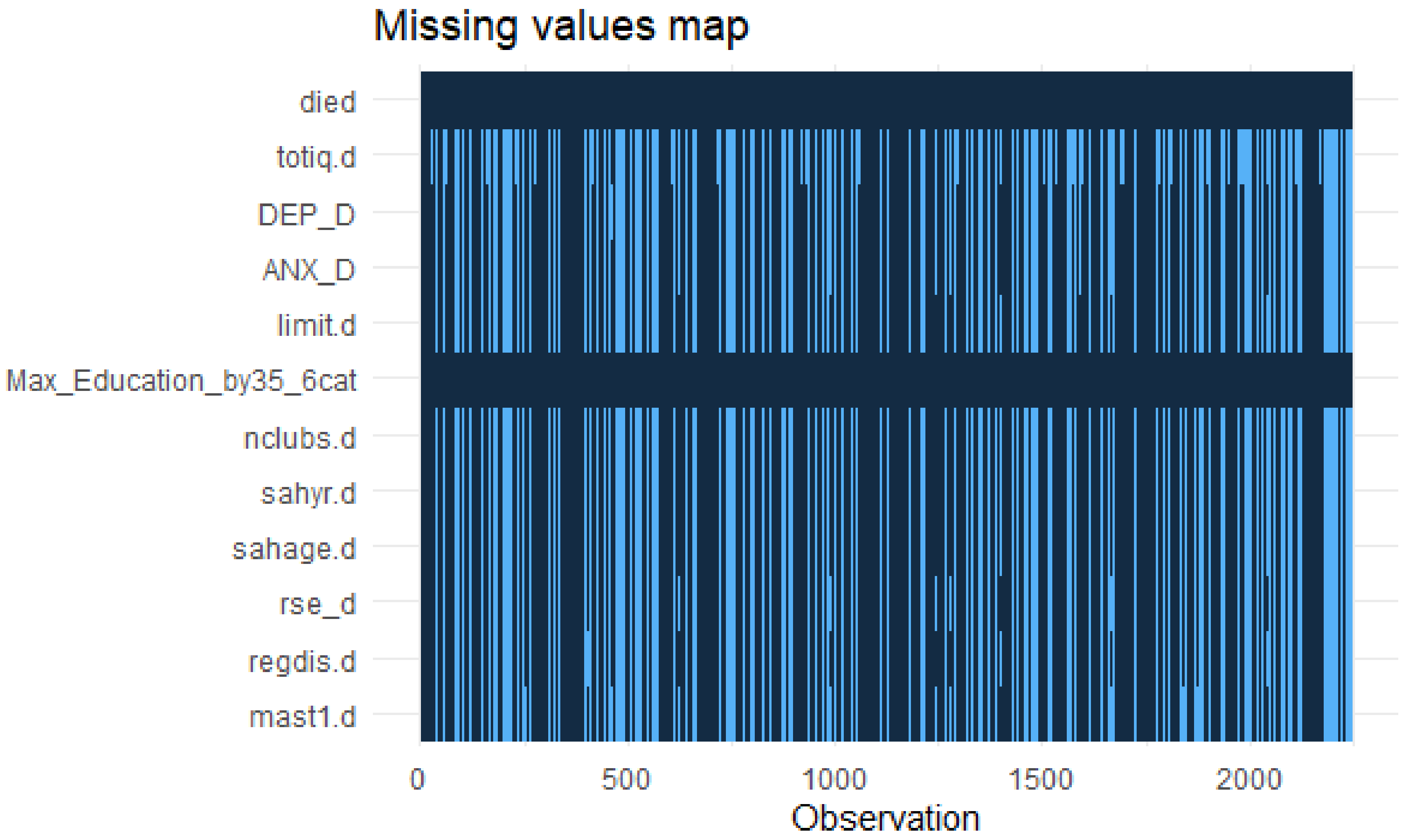

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Figure Figure A26: Figure demonstrating missingness pattern between variablesfor the expressing factors at wave 4

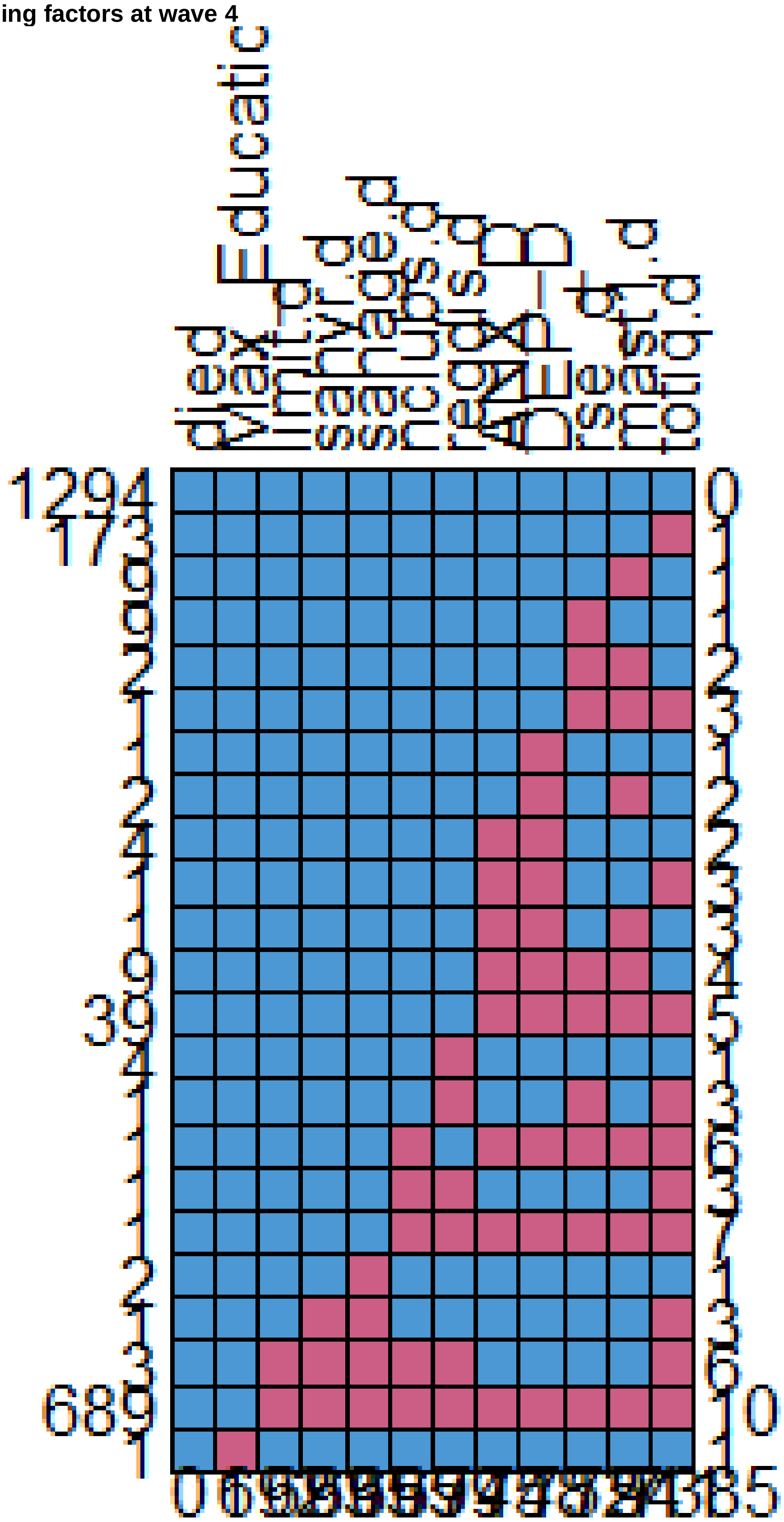


Figure A27: Figure demonstrating missingness for expressing capacity variables across the cohort at wave four.

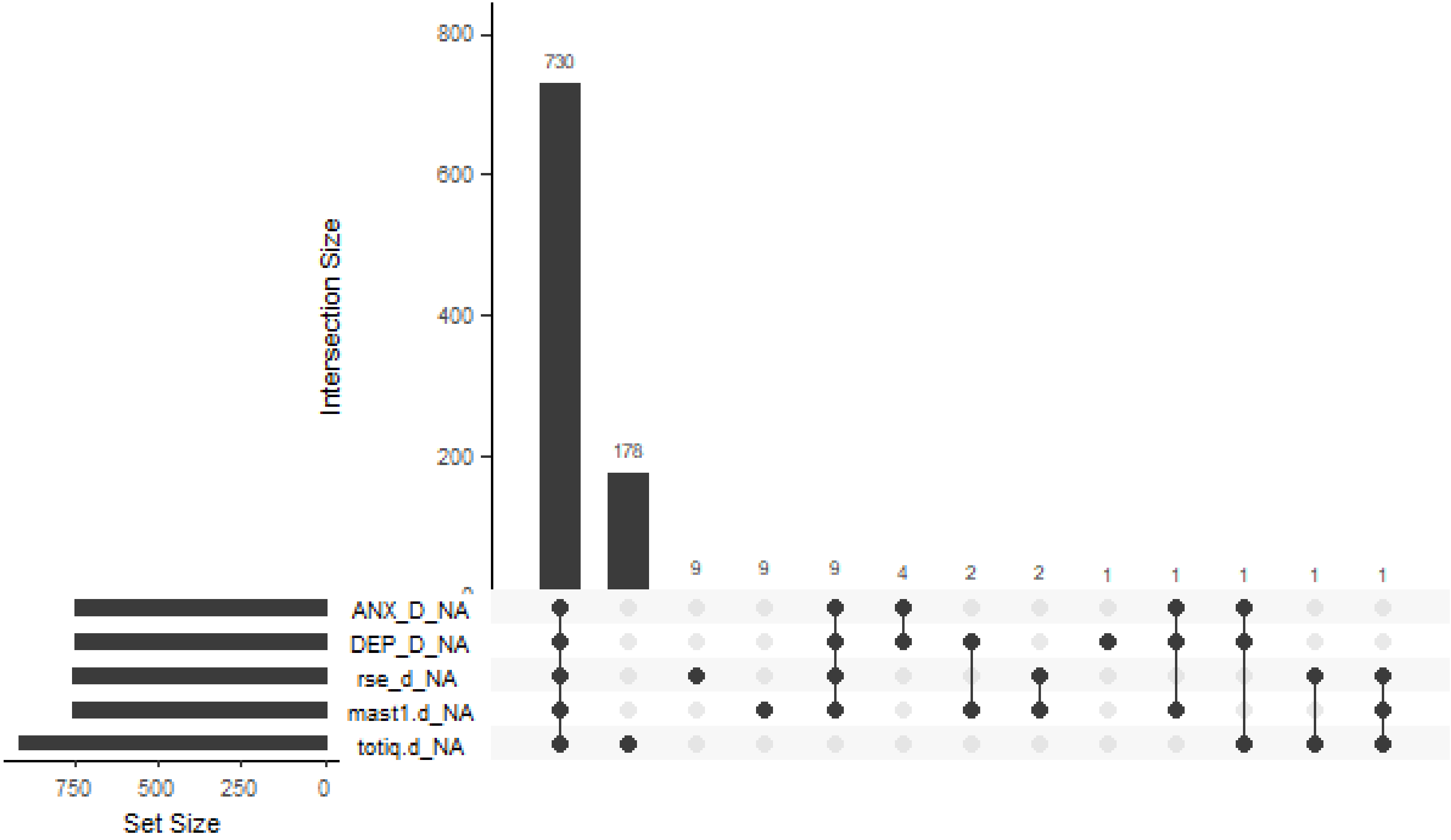


Figure A28: Figure demonstrating missingness for each expressing capacity variable across the cohort at wave five

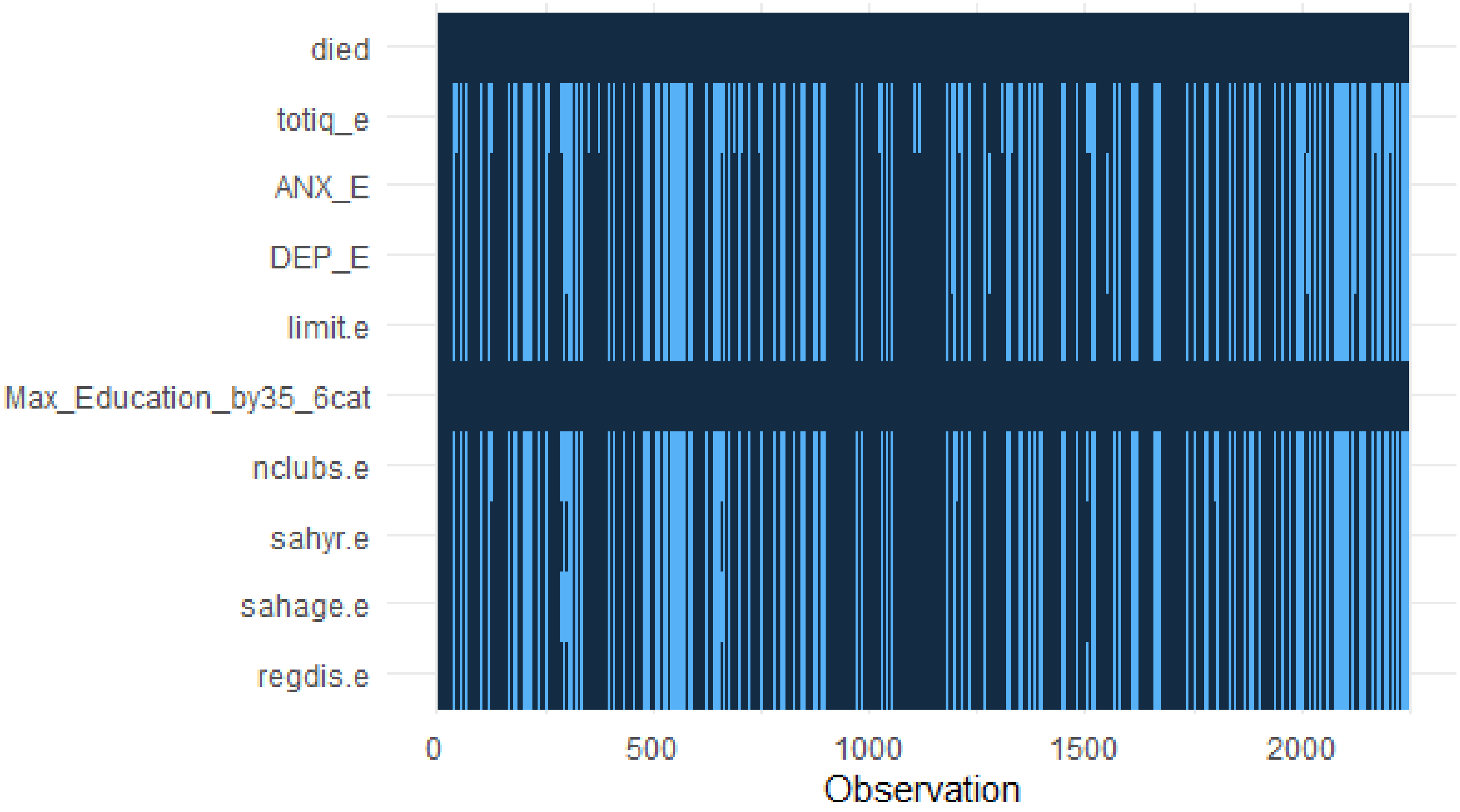


Figure 29 demonstrating missingness pattern between variablesfor the expressing factors at wave 5

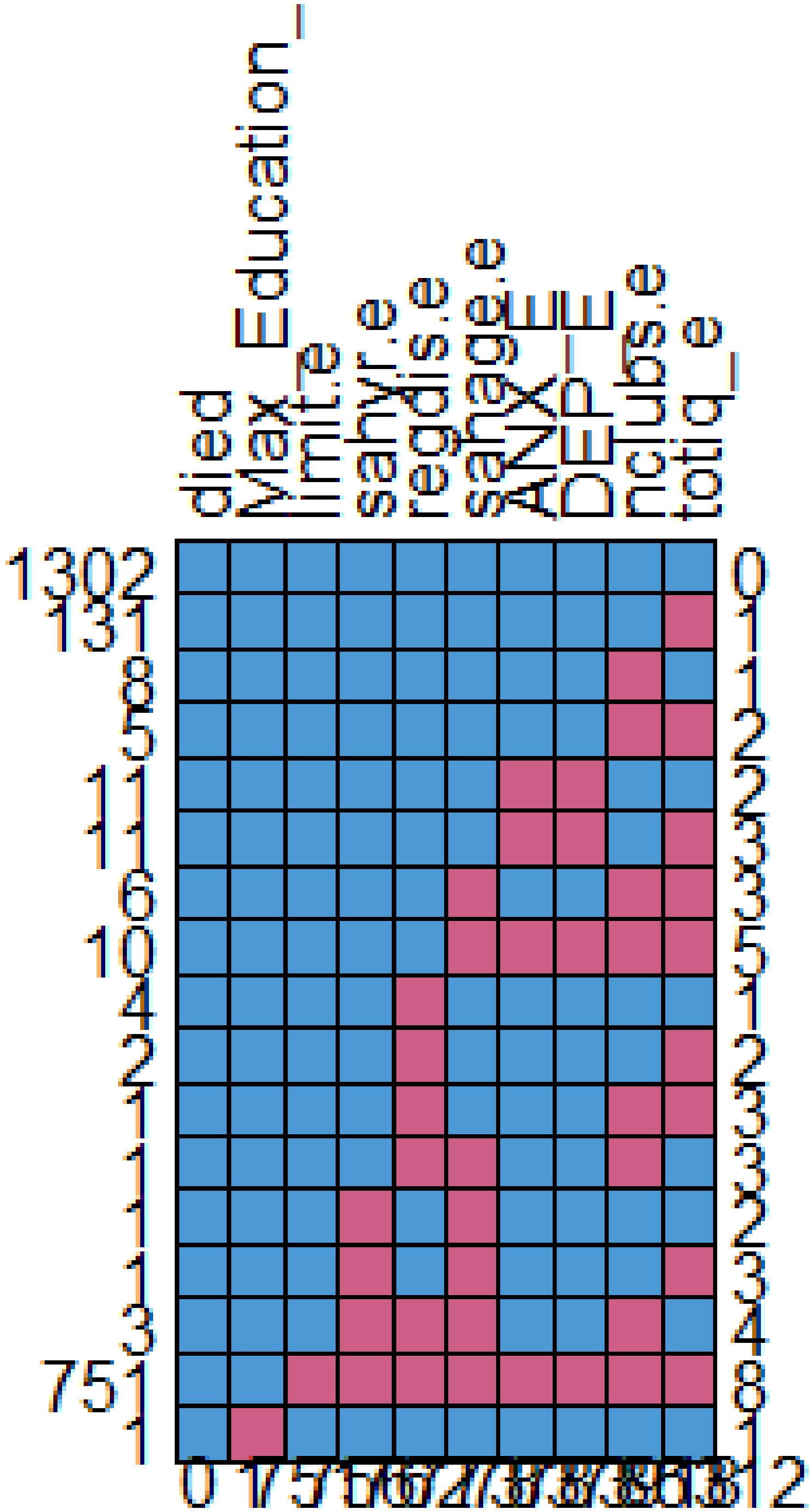
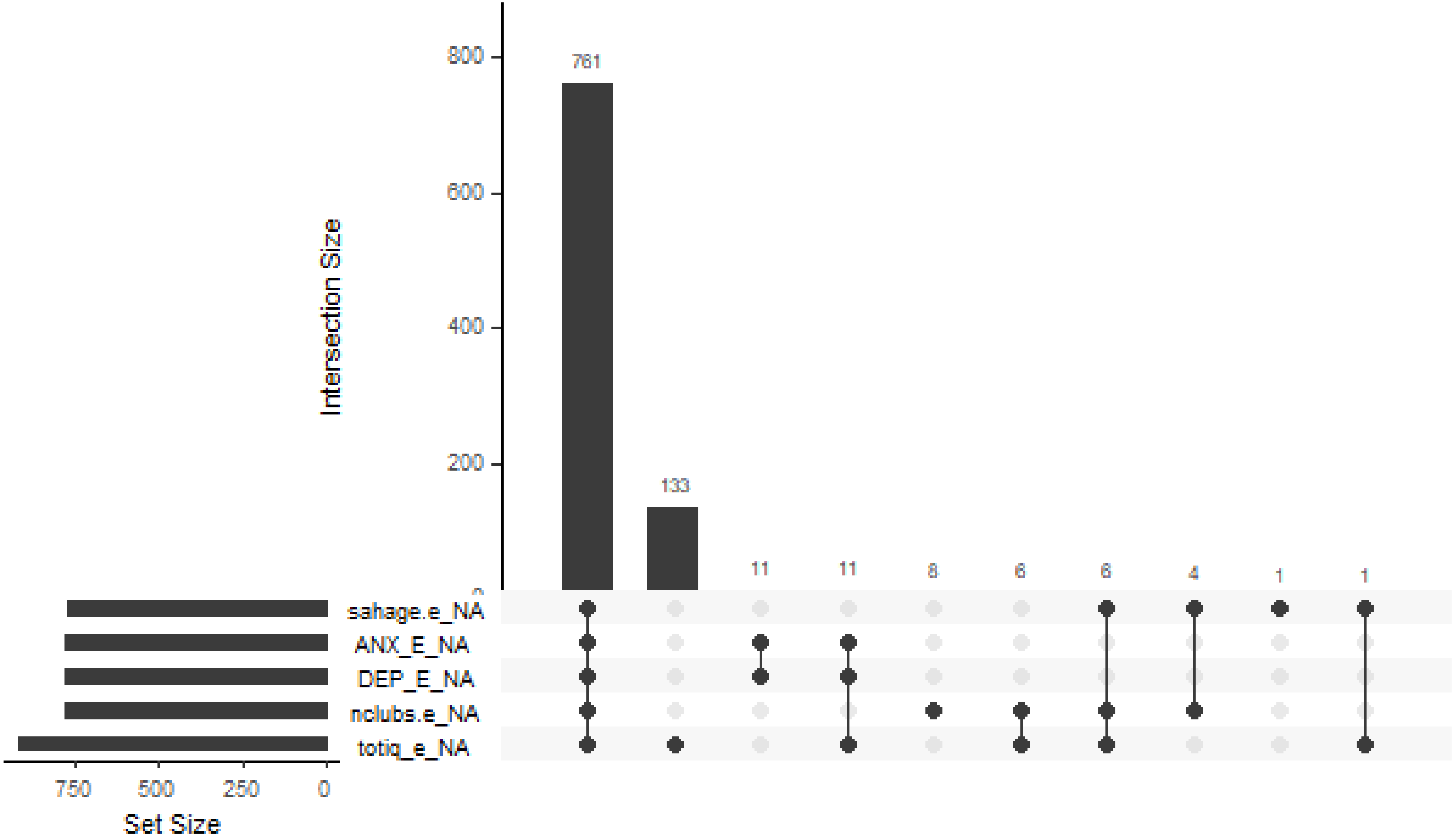


Figure A30: Figure demonstrating missingness for expressing capacity variables across the cohort at wave five



Community Capacity

Table A20- Table demonstrating whether community capacity variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at each wave

Wave 1						
	1930L	1930R	1950L	1950L	1970L[2]	1970R[2]
Neighbours	■	■				
Assault	■	■				
Burglary	■	■				
Disturbance	■	■				
fear dark	■	■				
feel area	■	■				
litter	■	■				
vandalism	■	■				
Wave 2						
Neighbours	■	■	■	■		
Assault	■	■	■	■		
Burglary	■	■	■	■		
Disturbance	■	■	■	■		
fear dark	■	■	■	■		
feel area	■	■	■	■		
litter	■	■	■	■		
vandalism	■	■	■	■		
Wave 3						
Neighbours[1]	■		■		■	
Assault	■	■	■	■	■	■
Burglary	■	■	■	■	■	■
Disturbance	■	■	■	■	■	■
fear dark	■	■	■	■	■	■
feel area	■	■	■	■	■	■
litter	■	■	■	■	■	■
vandalism	■	■	■	■	■	■
Waves 4 and 5						
Neighbours	■	■	■	■	■	■
Assault	■	■	■	■	■	■
Burglary	■	■	■	■	■	■
Disturbance	■	■	■	■	■	■
fear dark	■	■	■	■	■	■
feel area	■	■	■	■	■	■
litter	■	■	■	■	■	■
vandalism	■	■	■	■	■	■

Table A21– Table demonstrating the numbers collected and numbers, and percentages, missing for community capacity variables at baseline

Variable	Number	Missing (n)	Missing (%)
Neighbours	1126	1123	49.9
Feel Area	1125	1124	50
Walk in Dark	1125	1124	50
Assault	1123	1126	50.1
Burglary	1125	1124	50
Disturbance	1126	1123	49.9
Litter	1126	1123	49.9
Vandalism	1126	1123	49.9

Table A22– Table demonstrating the numbers collected and numbers, and percentages, missing for community capacity variables at Wave 2

Variable	Number	Missing (n)	Missing (%)
Neighbours	1678	7-571	25.4
Feel Area	1673	576	25.6
Walk in Dark	1673	576	25.6
Assault	1635	614	27.3
Burglary	1655	594	26.4
Disturbance	1669	580	25.8
Litter	1674	575	25.6
Vandalism	1665	584	26

Table A23– Table demonstrating the numbers collected and numbers, and percentages, missing community capacity variables at Wave 3

Variable	Number	Missing (n)	Missing (%)
Neighbours	470	1779	79.1
Feel area	1707	542	25.1
Fear Dark	1708	541	241.
Assault	1679	570	25.3
Burglary	1679	570	25.3
Disturbance	1694	555	24.7
Litter	1702	547	24.3
Vandalism	1702	547	24.3

Table A24– Table demonstrating the numbers collected and numbers, and percentages, missing community capacity variables at Wave 4

Variable	Number	Missing (n)	Missing (%)
Neighbours	1554	695	30.9
Feel Area	1552	699	31.1
Walk in dark	1536	713	31.7
Assault	1345	904	40.2
Burglary	1522	727	32.3
Disturbance	1550	699	31.1
Litter	1552	697	31
Vandalism	1545	704	31.3

Table A25– Table demonstrating the numbers collected and numbers, and percentages, missing for community capacity variables at Wave 5

Variable	**Number**	**Missing (n)**	**Missing (%)**
Neighbours	1491	758	33.7
Feel Area	1457	792	35.2
Walk in dark	1462	787	35
Assault	1427	822	36.5
Burglary	1417	832	37
Disturbance	1461	788	35
Litter	1463	786	34.9
Vandalism	1453	796	35.3

Figure A31: Figure demonstrating missingness for community capacity variables across the cohort at wave five

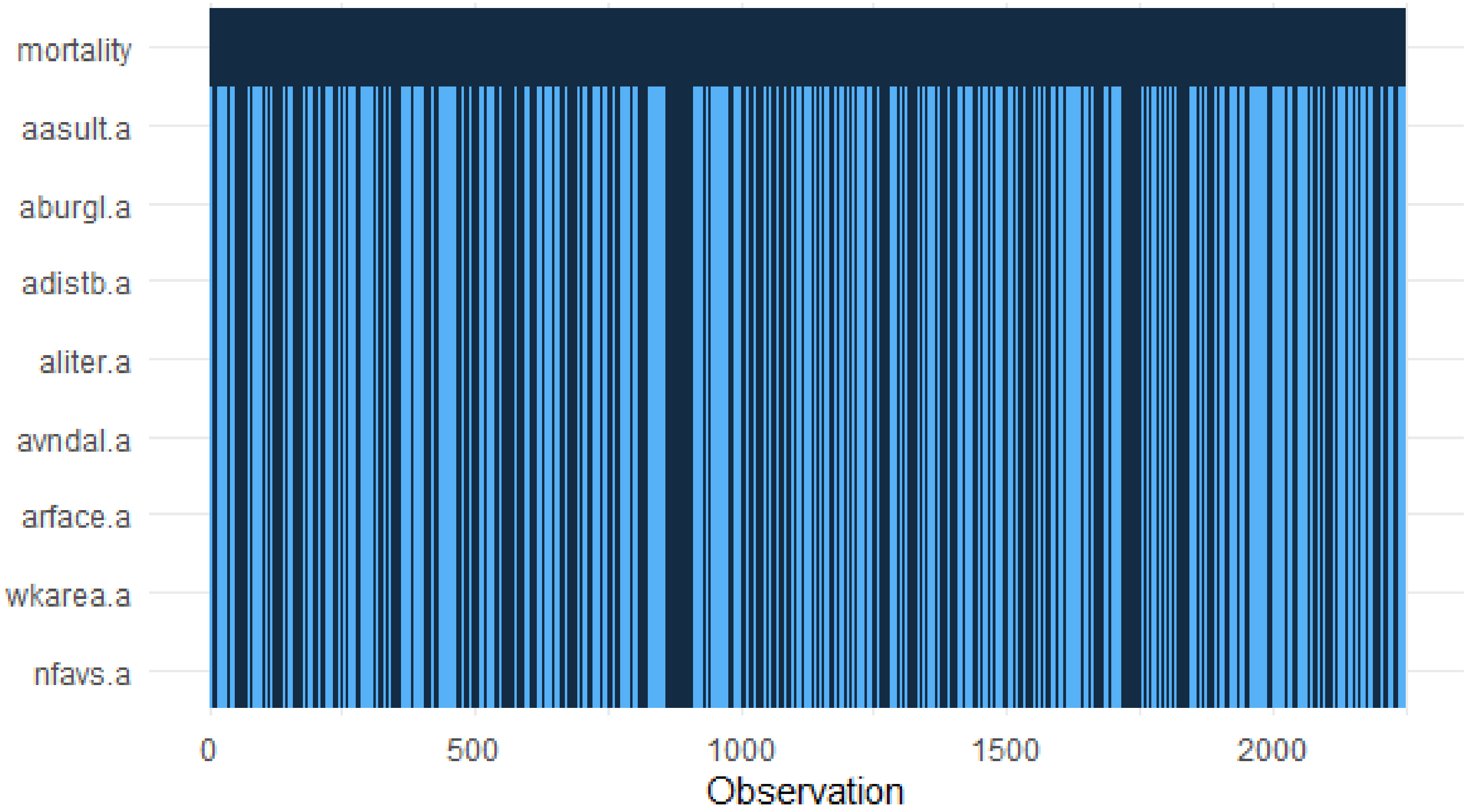


Figure A32: Figure demonstrating missingness for community capacity variables across the cohort at baseline

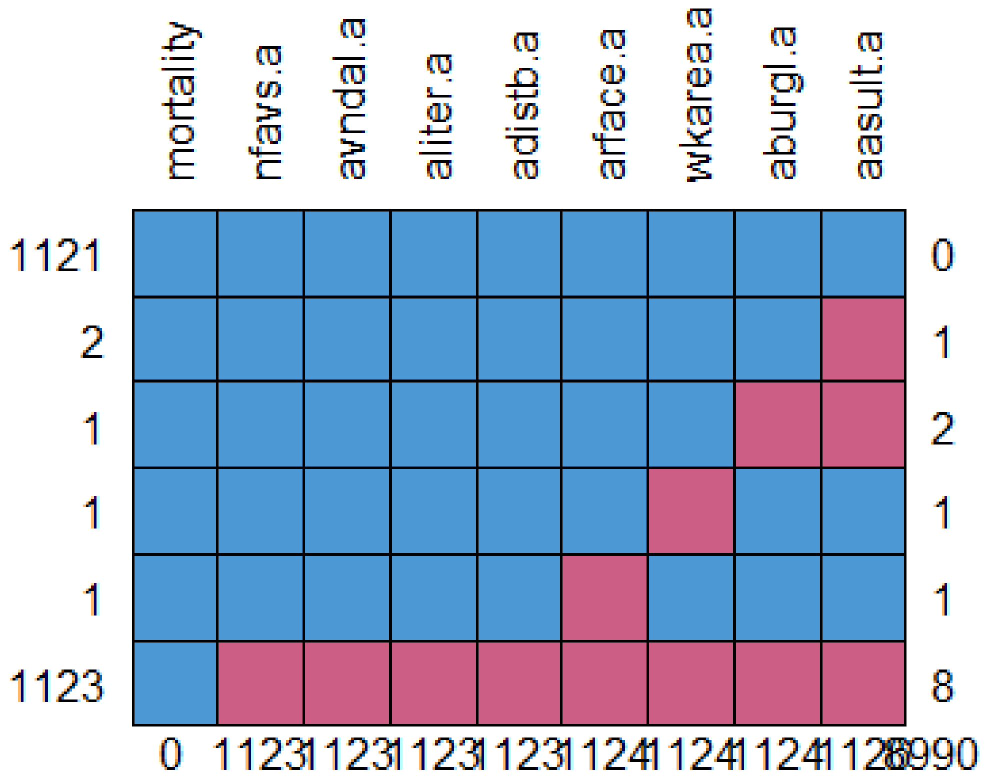


Figure A33: Figure demonstrating missingness for community capacity variables across the cohort at baseline

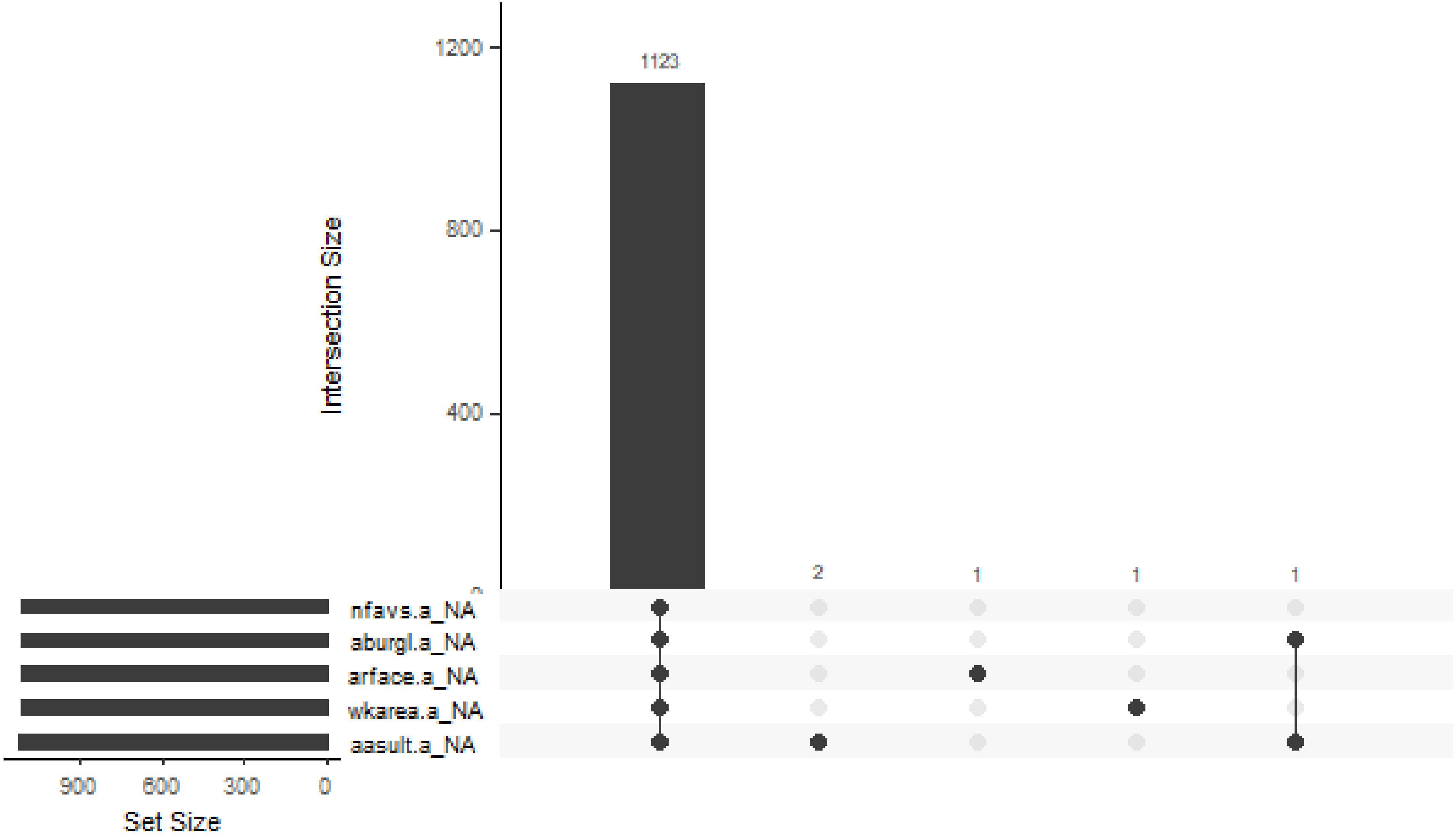


Figure A34: Figure demonstrating missingness for community capacity variables across the cohort at wave two

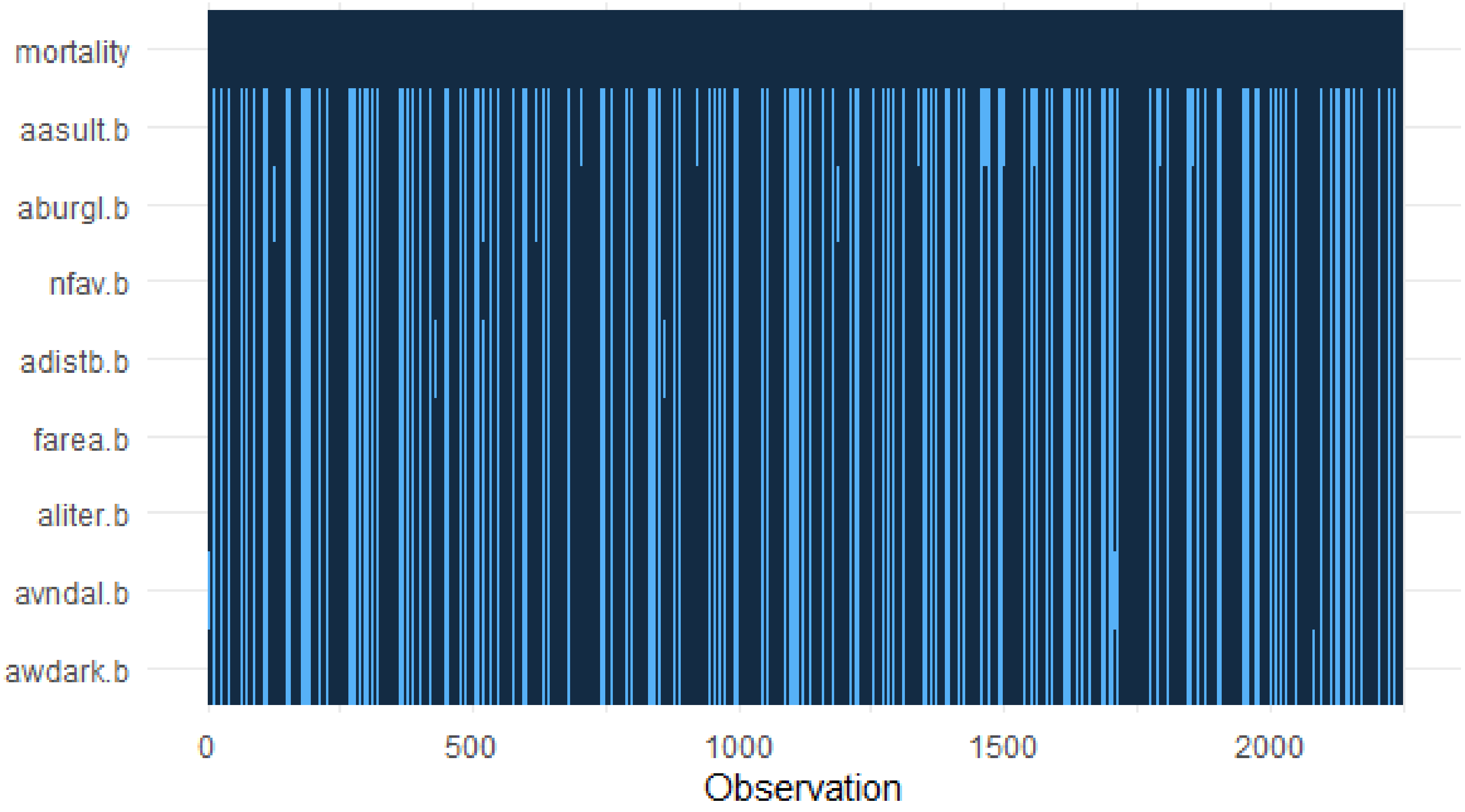


Figure A35: Figure demonstrating missingness for community capacity variables across the cohort at wave two

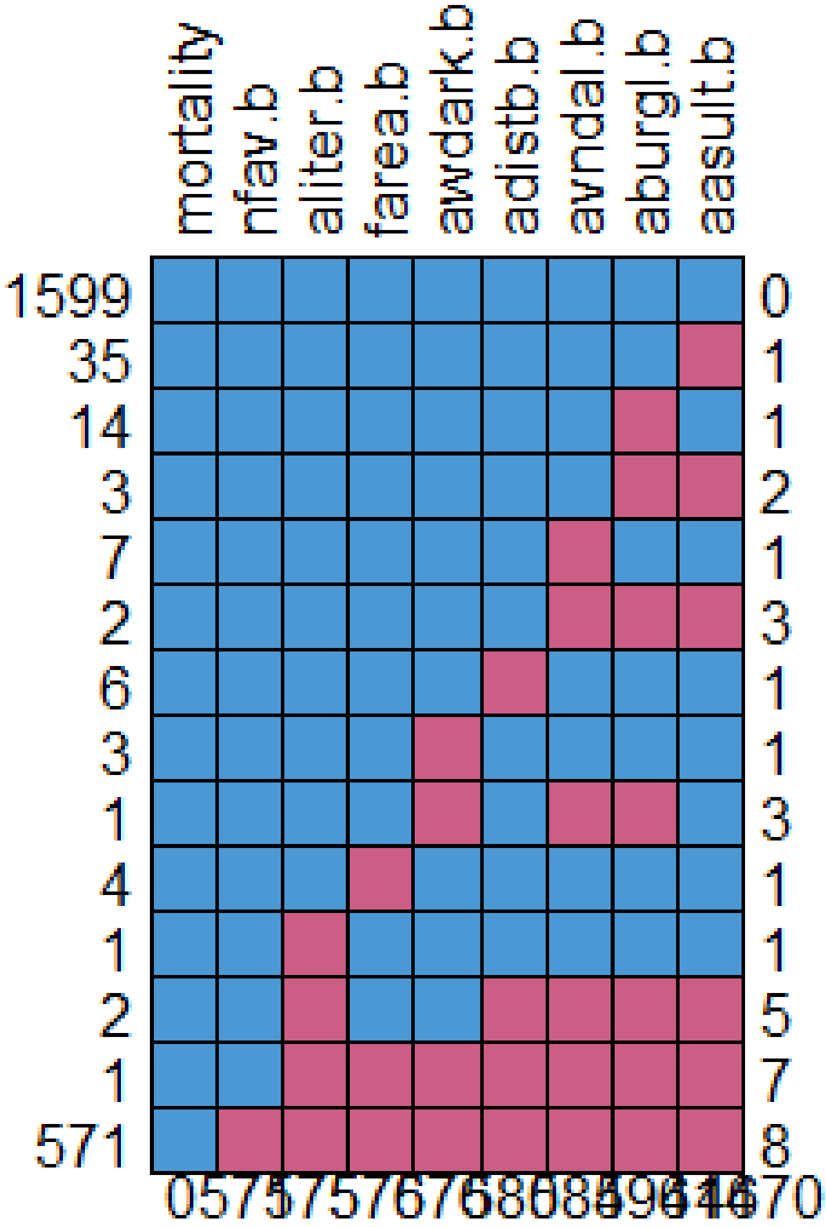


Figure A35: Figure demonstrating missingness for community capacity variables across the cohort at wave two

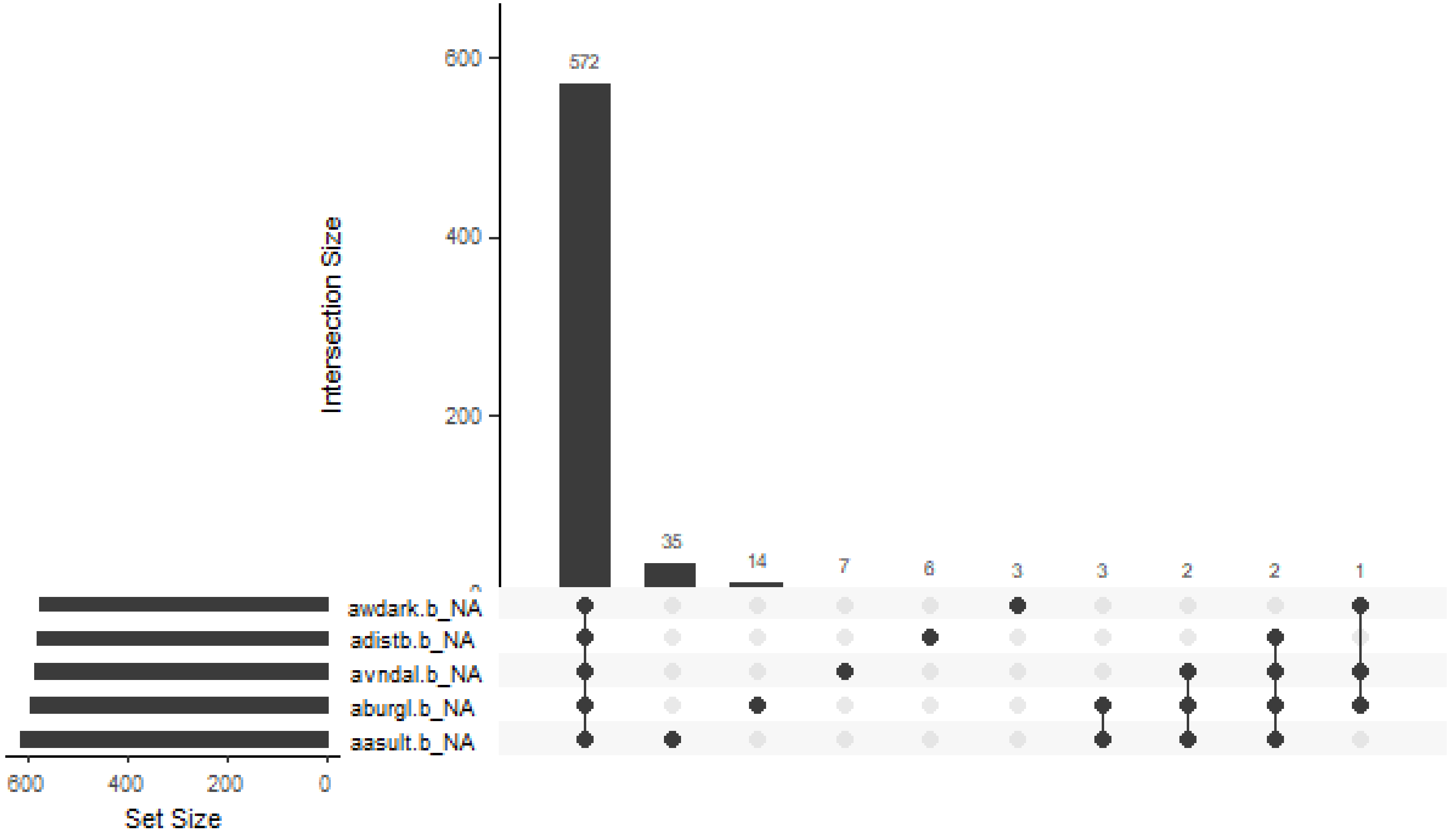


Figure A36: Figure demonstrating missingness for community capacity variables across the cohort at wave three

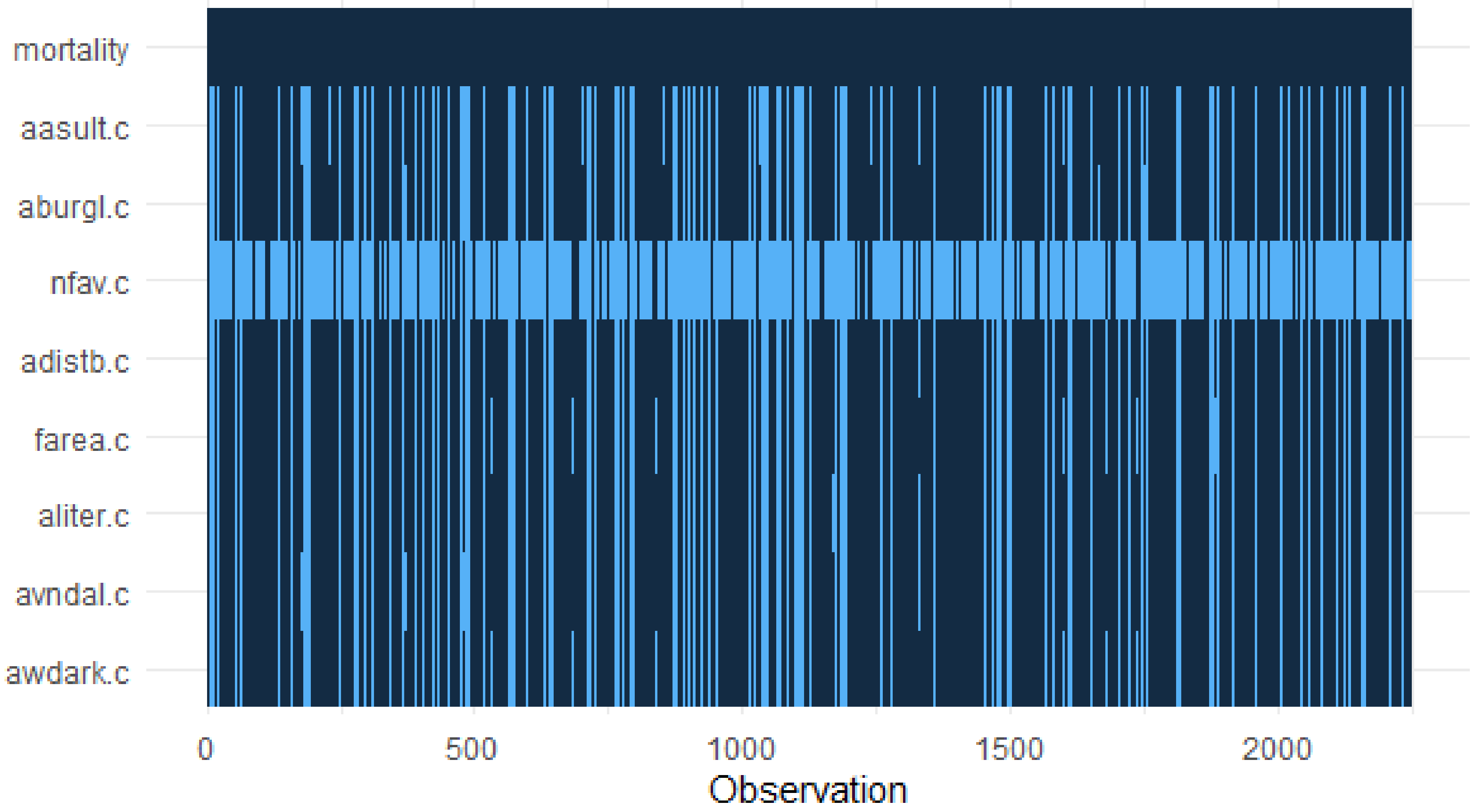


Figure A37: Figure demonstrating missingness for community capacity variables across the cohort at wave two

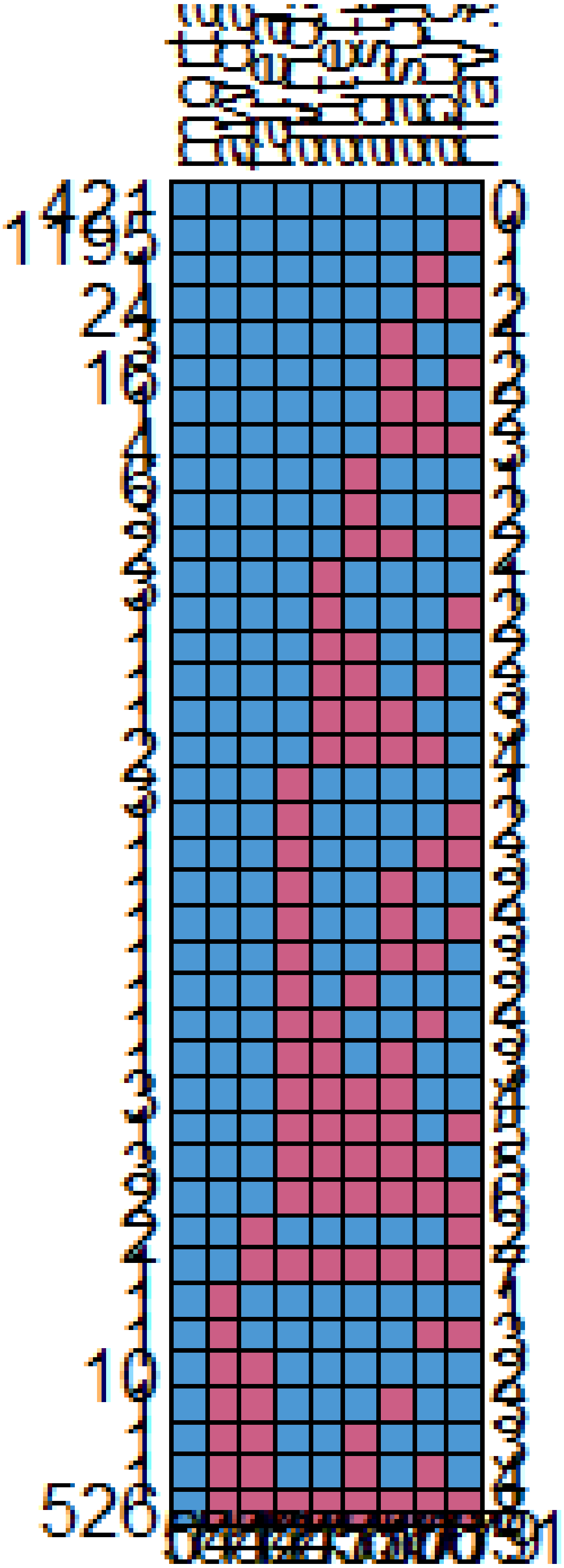


Figure A38: Figure demonstrating missingness for community capacity variables across the cohort at wave three

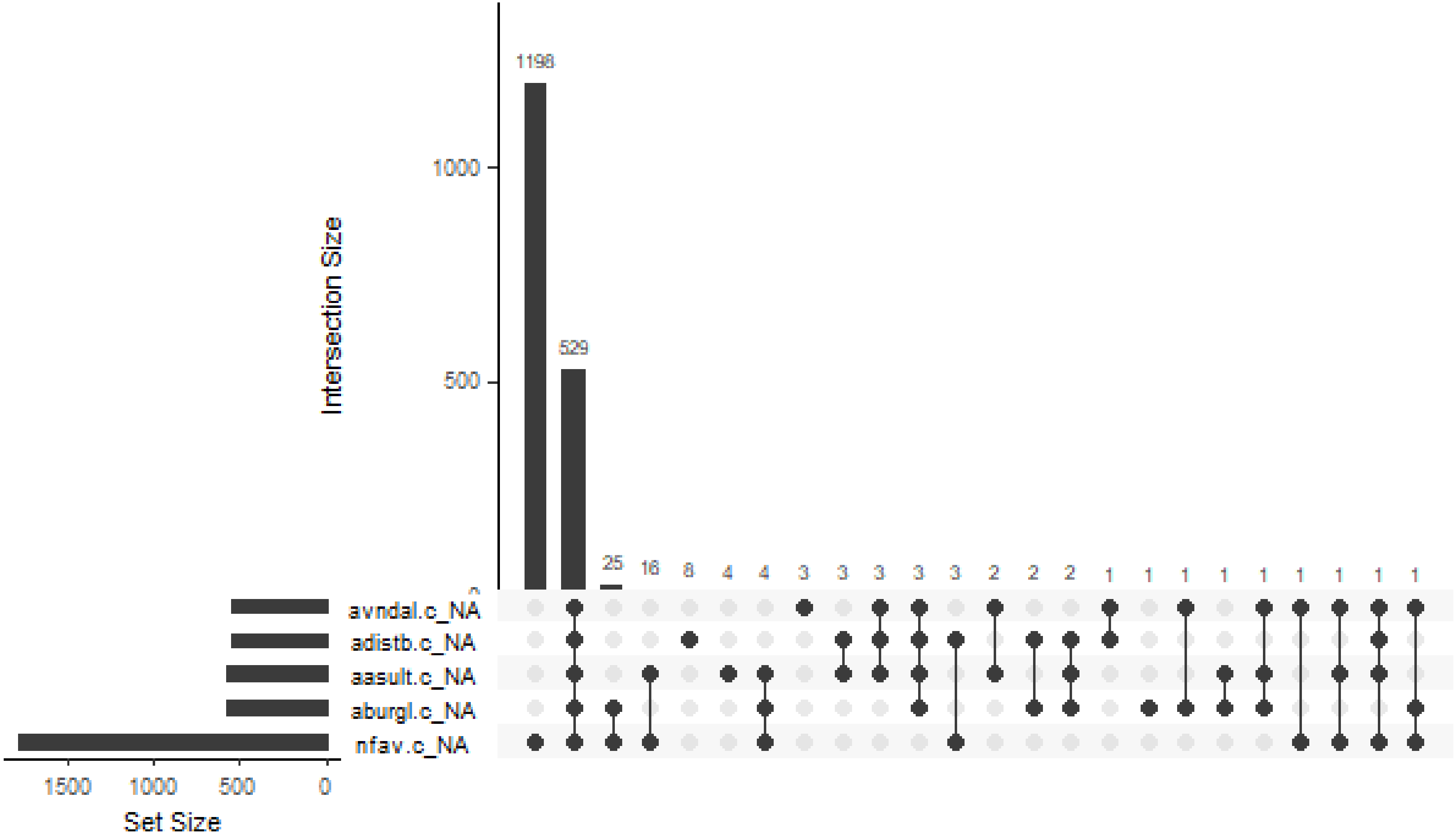


Figure A39: Figure demonstrating missingness for community capacity variables across the cohort at wave four

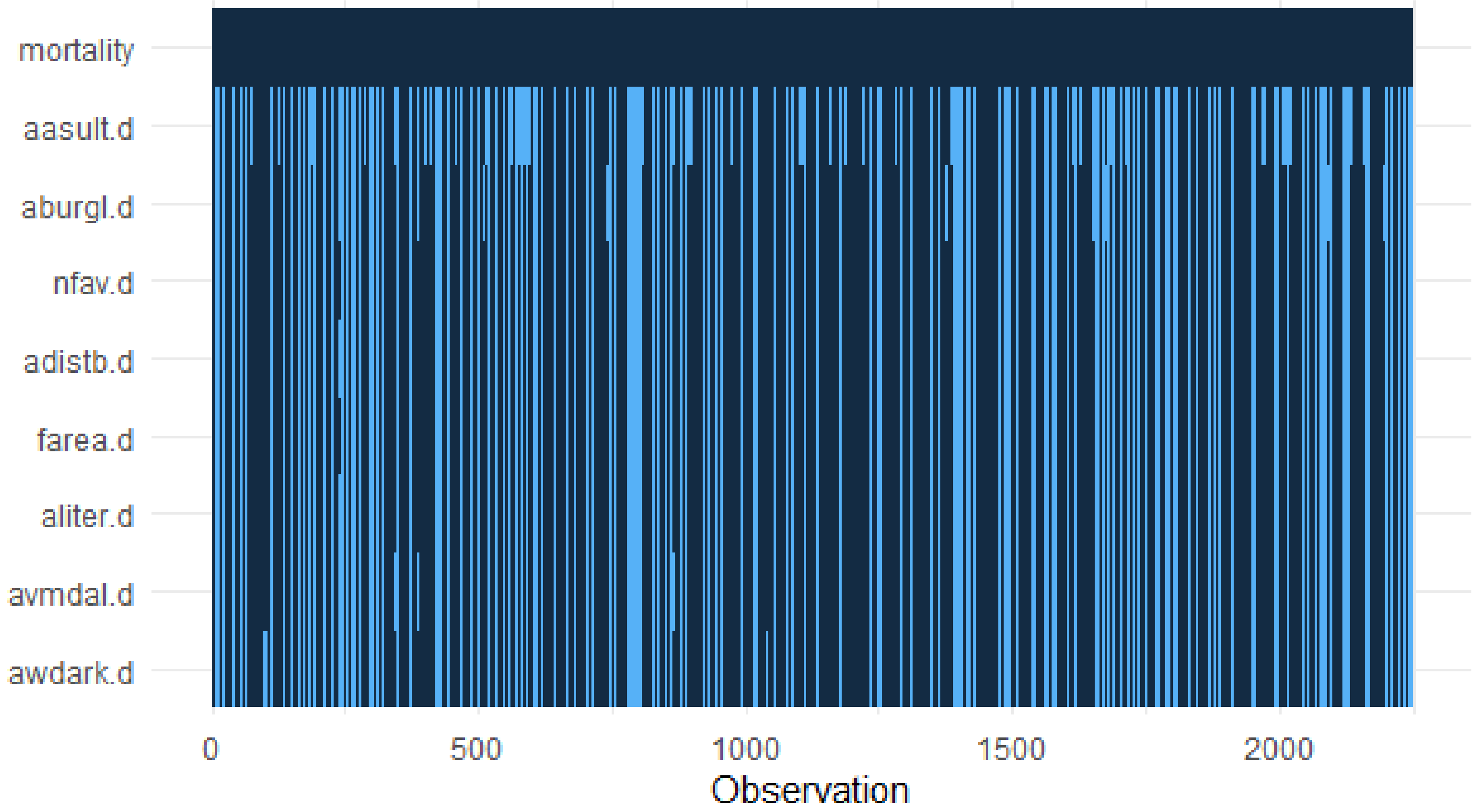


Figure A40: Figure demonstrating missingness for community capacity variables across the cohort at wave four

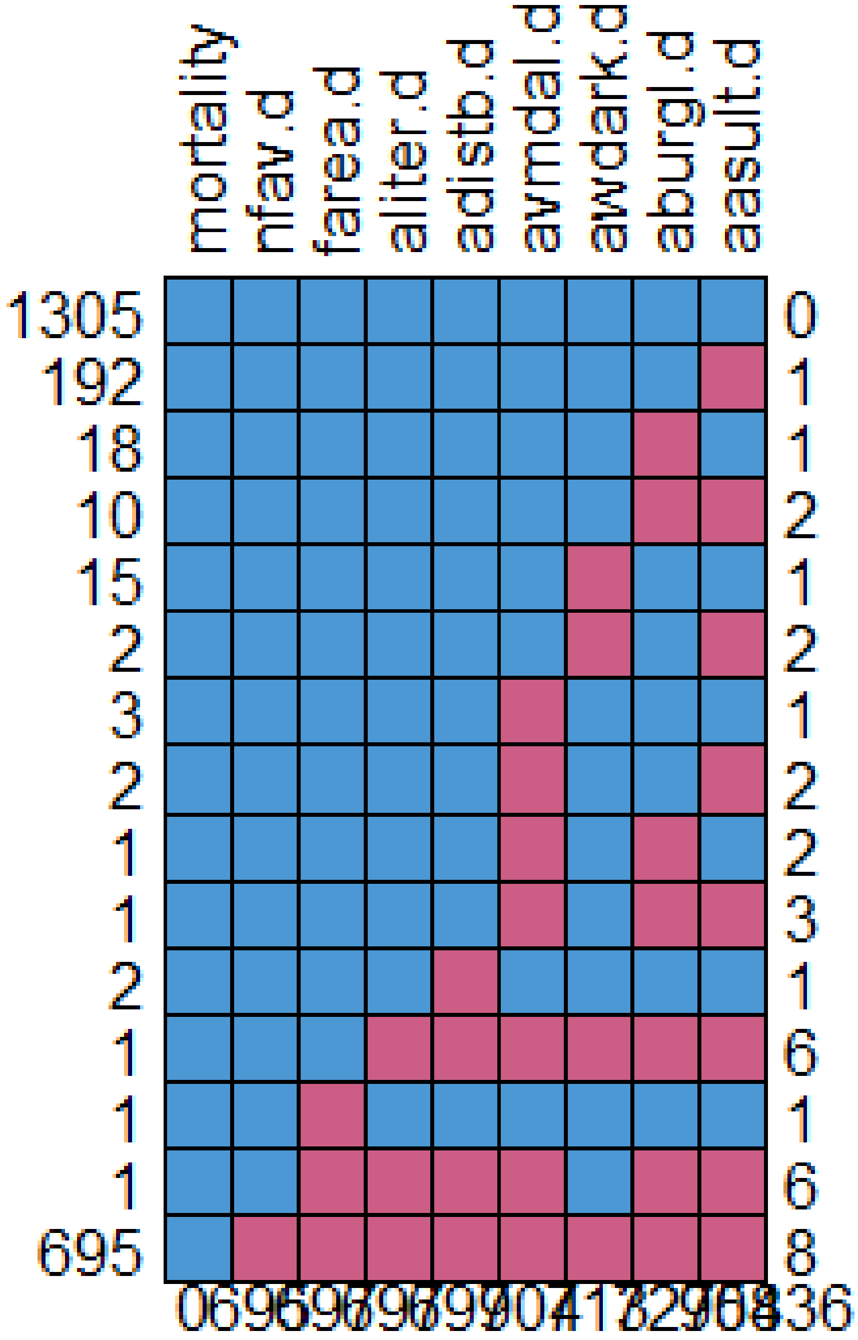


Figure A41: Figure demonstrating missingness for community capacity variables across the cohort at wave four

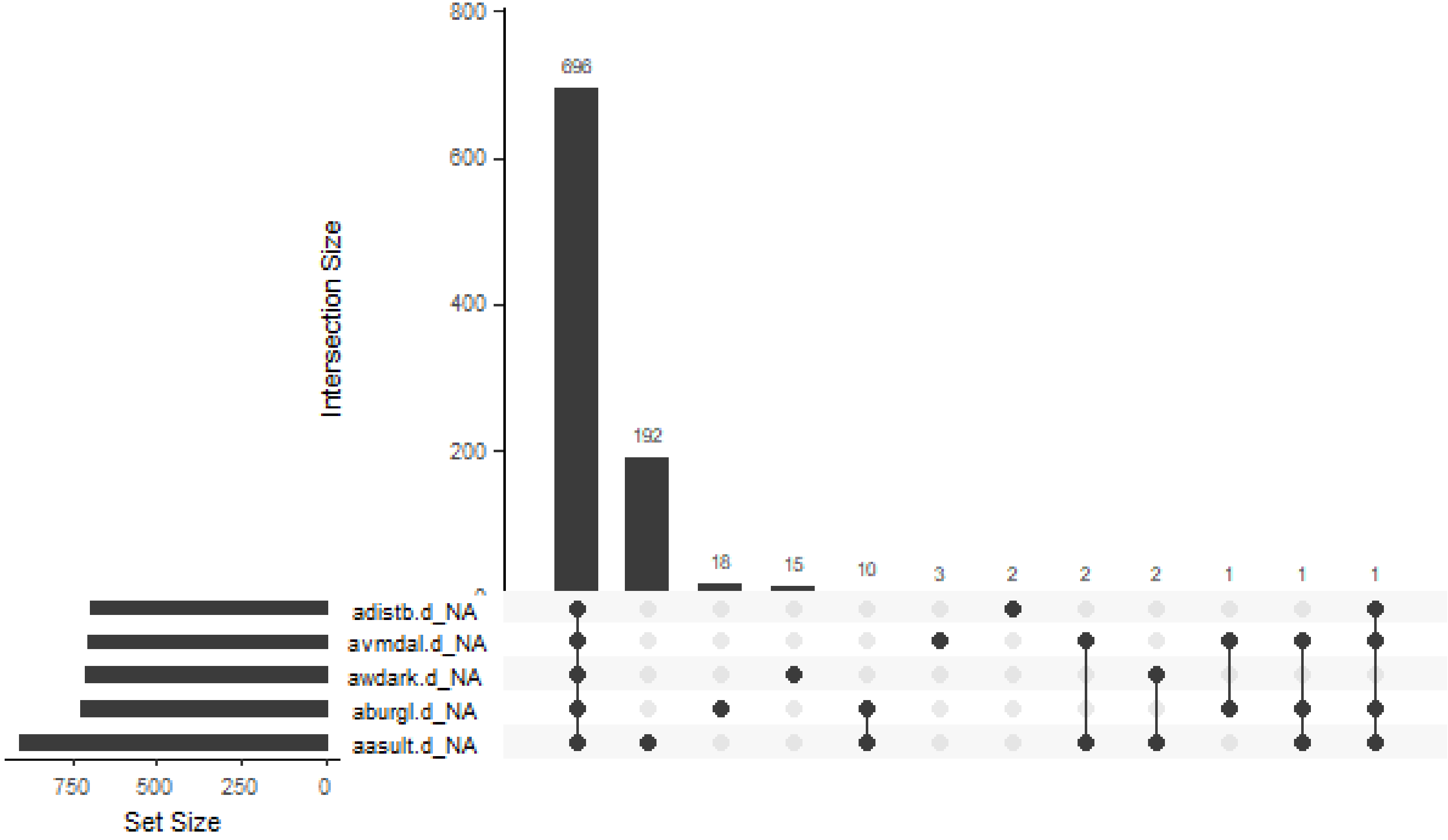


Figure A42: Figure demonstrating missingness for community capacity variables across the cohort at wave five

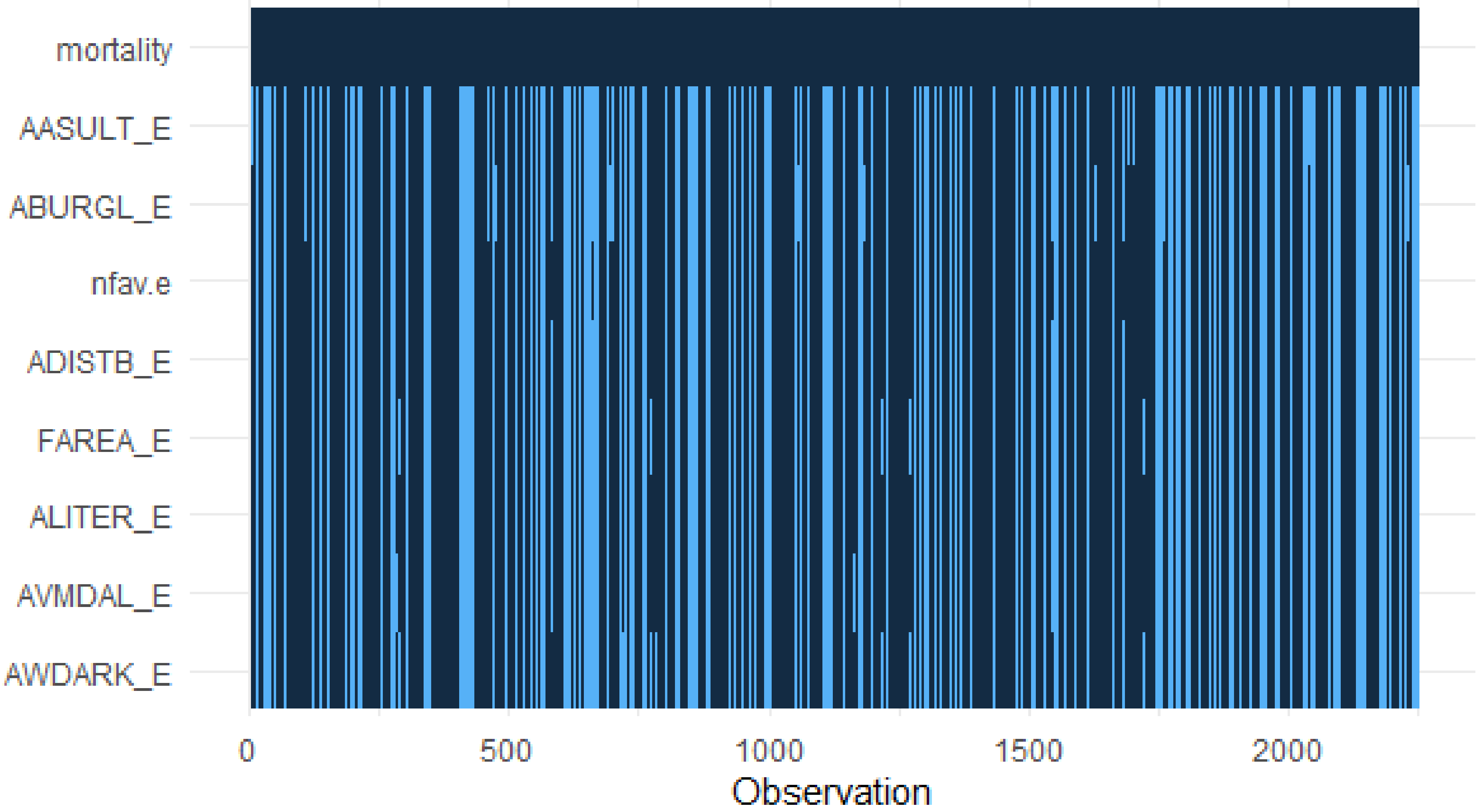


Figure A43: Figure demonstrating missingness for community capacity variables across the cohort at wave five

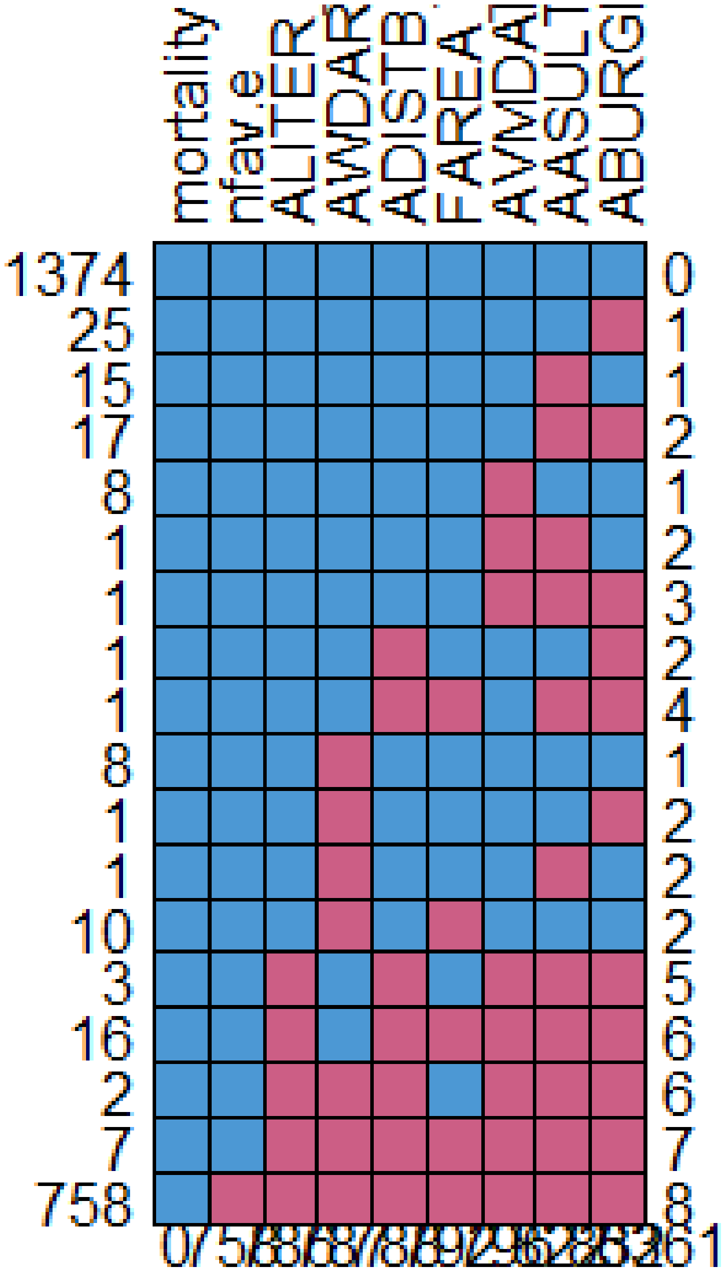
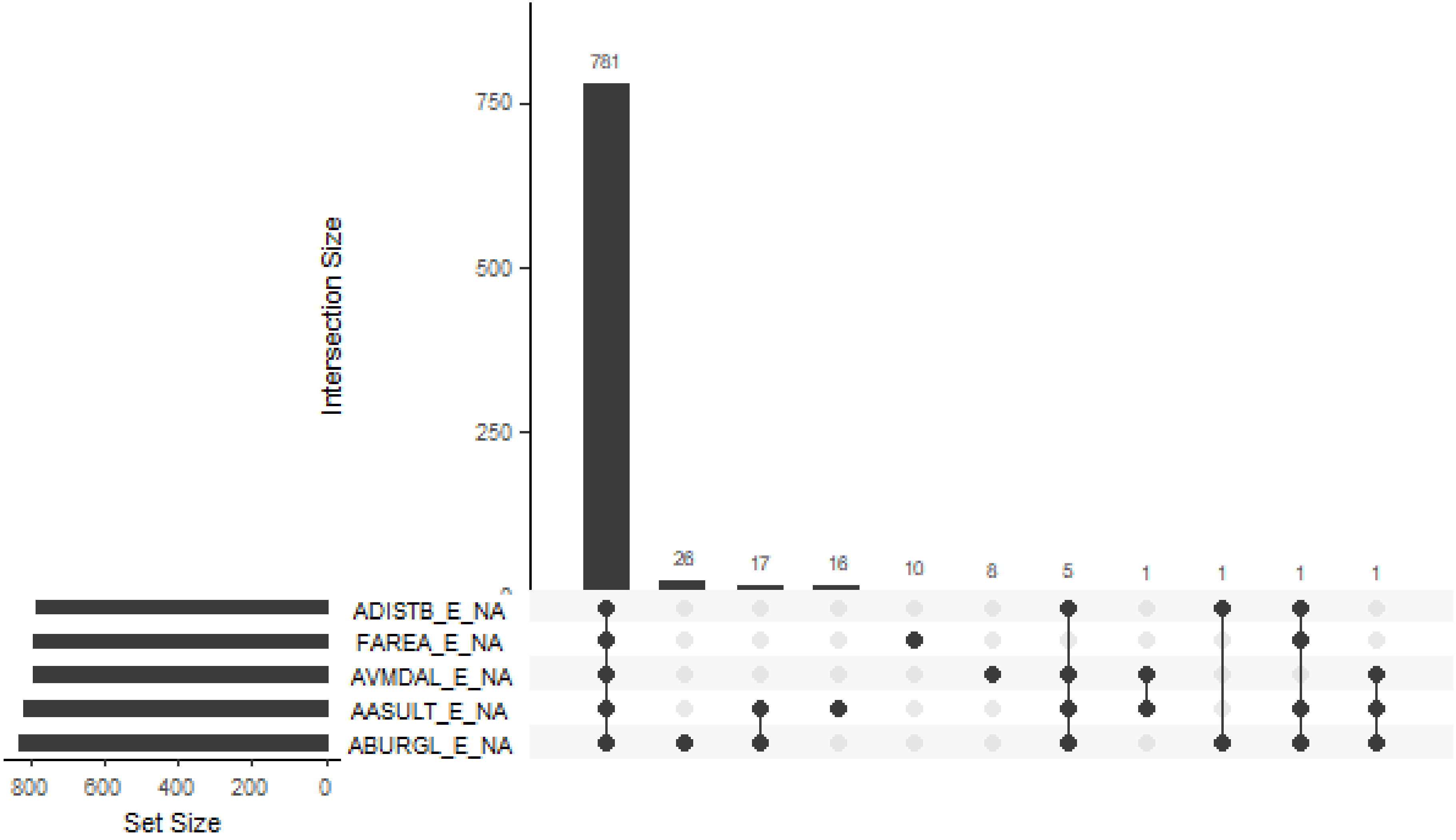


Figure A45: Figure demonstrating missingness for community capacity variables across the cohort at wave five



Treatment Burden

Table A26- Table demonstrating whether treatment burden variable information was asked about by cohort (1930/50/70) and location – regional (R) or locality (L) at each wave

Wave 1						
	1930 L	1930 R	1950 L	1950 R	1970 L	1970 R
Outpatient in last year	■	■				
Number Medications	■	■	■	■	■	■
GP visits in last year	■	■	■	■	■	■
Wave 2						
Outpatient in last year	■	■	■	■		
Number Medications	■	■	■	■	■	■
GP visits in last year	■	■	■	■	■	■
Wave 3						
Outpatient in last year		■		■		■
Number Medications		■		■		■
GP visits in last year	■	■	■	■	■	■
Waves 4 and 5						
Outpatient in last year	■	■	■	■	■	■
Number Medications	■	■	■	■	■	■
GP visits in last year	■	■	■	■	■	■

Table A27– Table demonstrating the numbers collected and numbers, and percentages, missing for treatment burden variables across the waves

Variable	Number	Missing (n)	Missing (%)
Wave 1			
Outpatient in last year	703	1546	68.7
Number Medications	2249	0	0
GP visits in last year	2190	59	2.6
Wave 2			
Outpatient in last year	1674	575	25.6
Number Medications	2057	192	8.5
GP visits in last year	2038	211	9.4
Wave 3			
Outpatient in last year	1254	995	44.2
Number Medications	1727	522	23.2
GP visits in last year	1715	534	23.7
Wave 4			
Outpatient in last year	1557	692	30.8
Number Medications	1552	697	31.0
GP visits in last year	1560	689	30.6
Wave 5			
Outpatient in last year	1489	760	33.8
Number Medications	1498	751	33.4
GP visits in last year	1487	762	33.9

Figure A46: Figure demonstrating missingness for treatment burden variable across the cohort at baseline

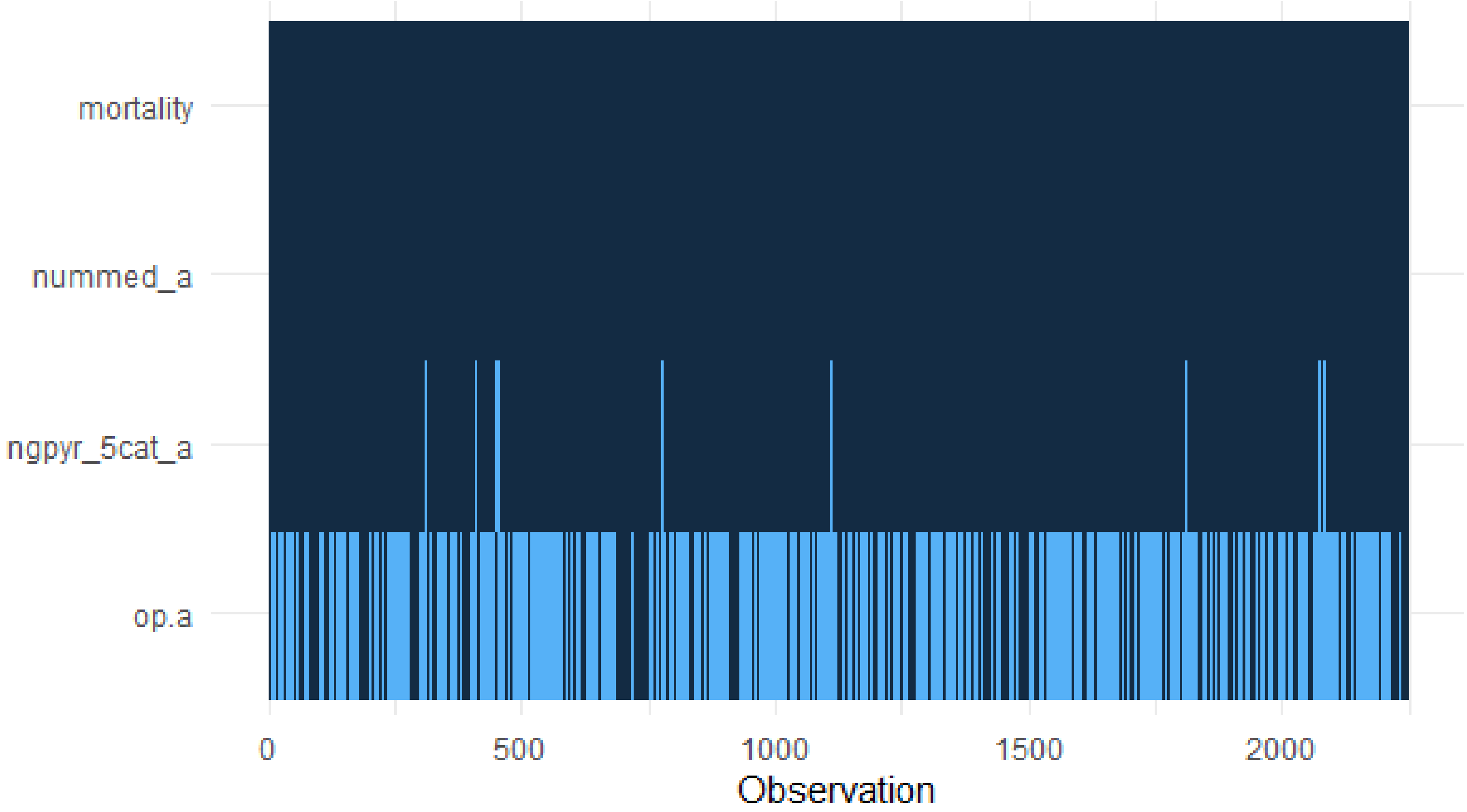


Figure A47 : Figure demonstrating missingness for treatment burden variables across the cohort at baseline

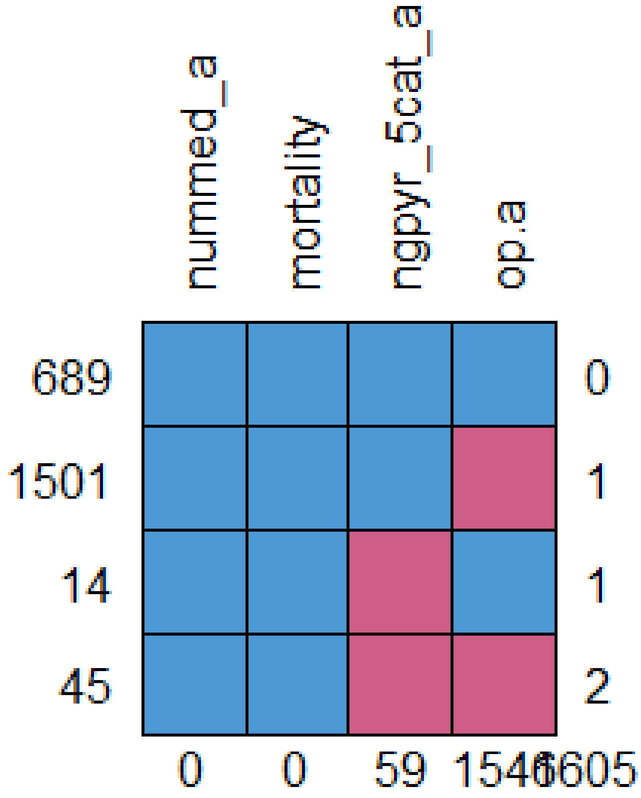


Figure A48 : Figure demonstrating missingness for treatment burden variables across the cohort at baseline

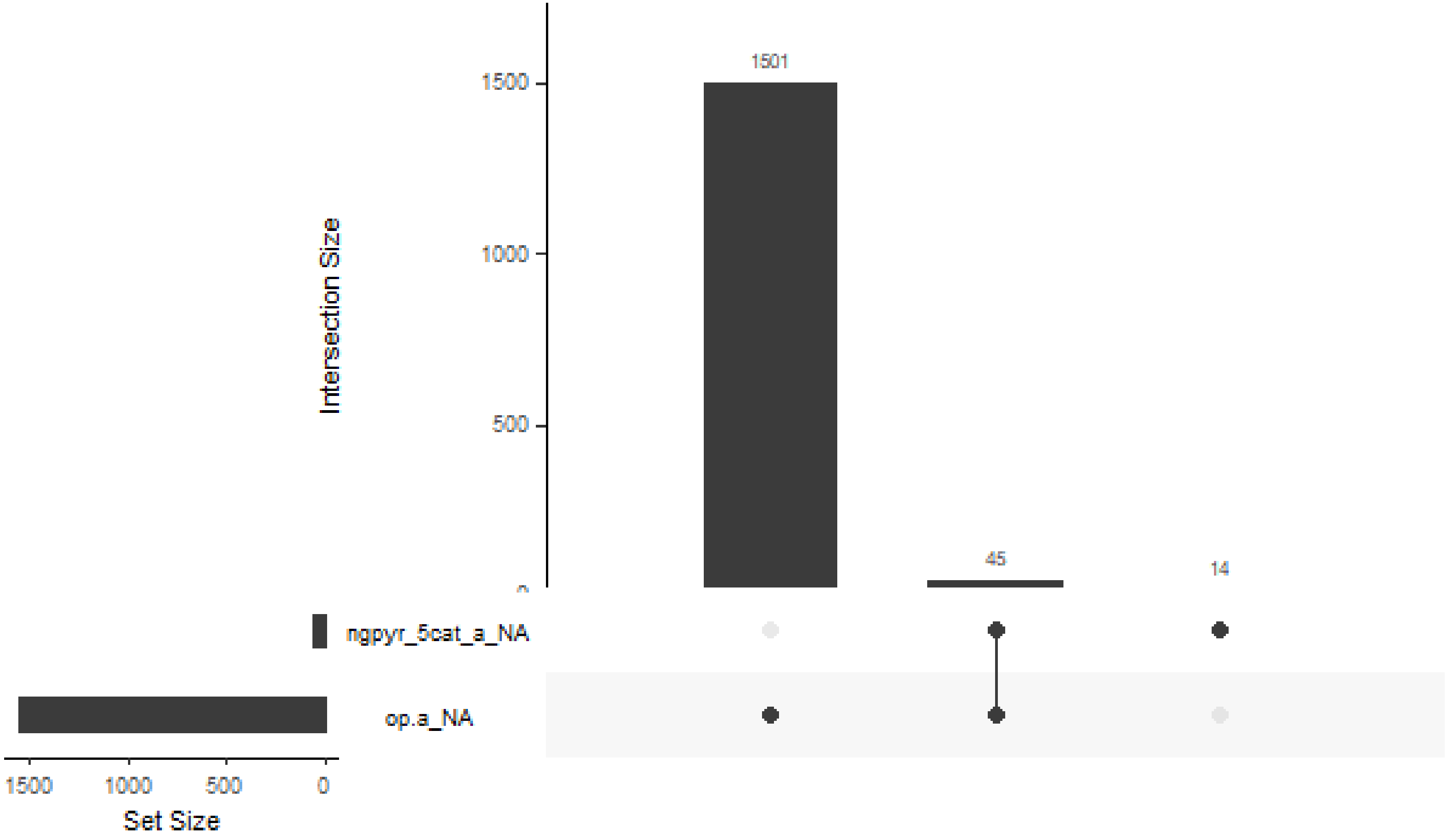


Figure A49: Figure demonstrating missingness for treatment burden variables across the cohort at wave two

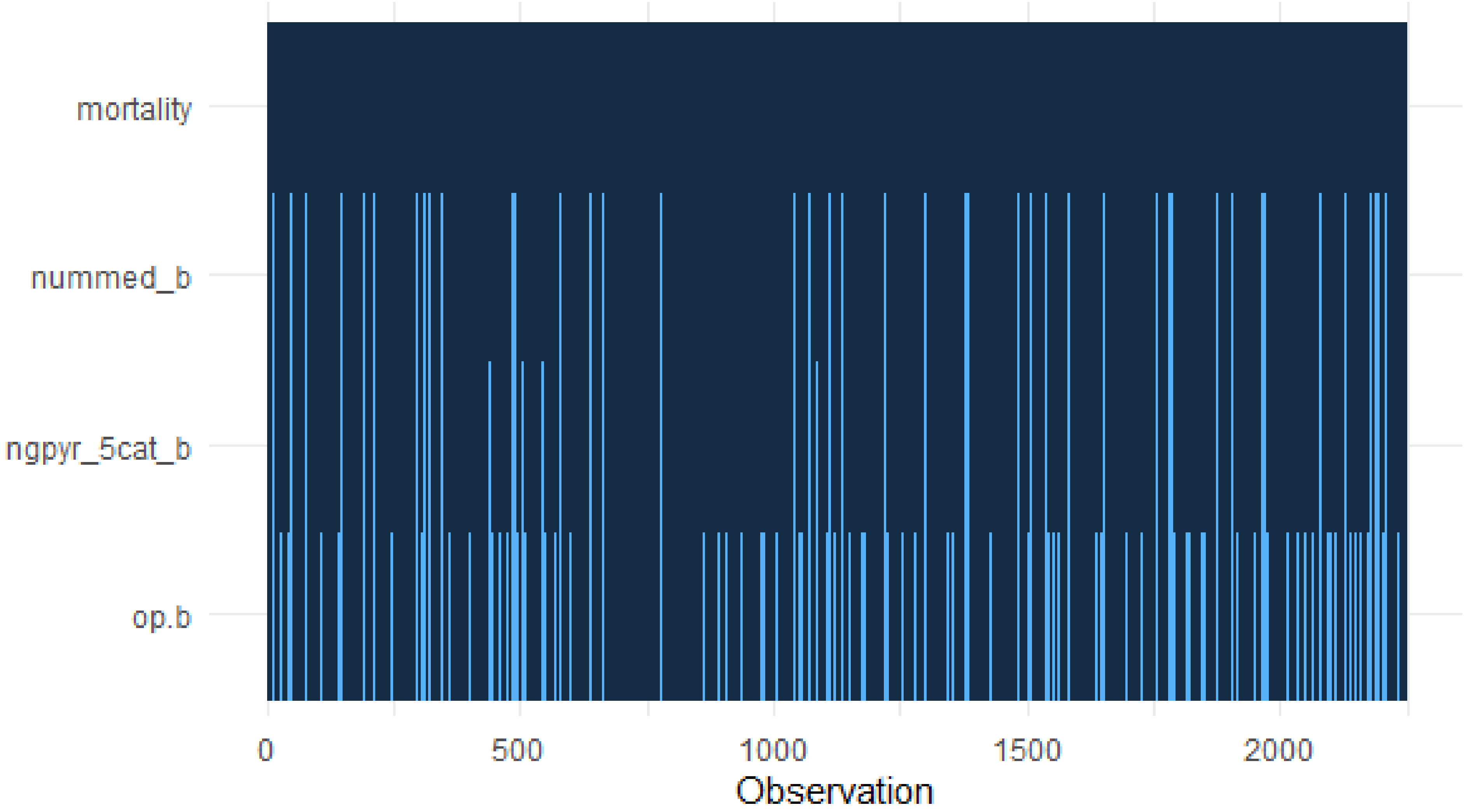


Figure A50 : Figure demonstrating missingness for treatment burden variables across the cohort at wave 2

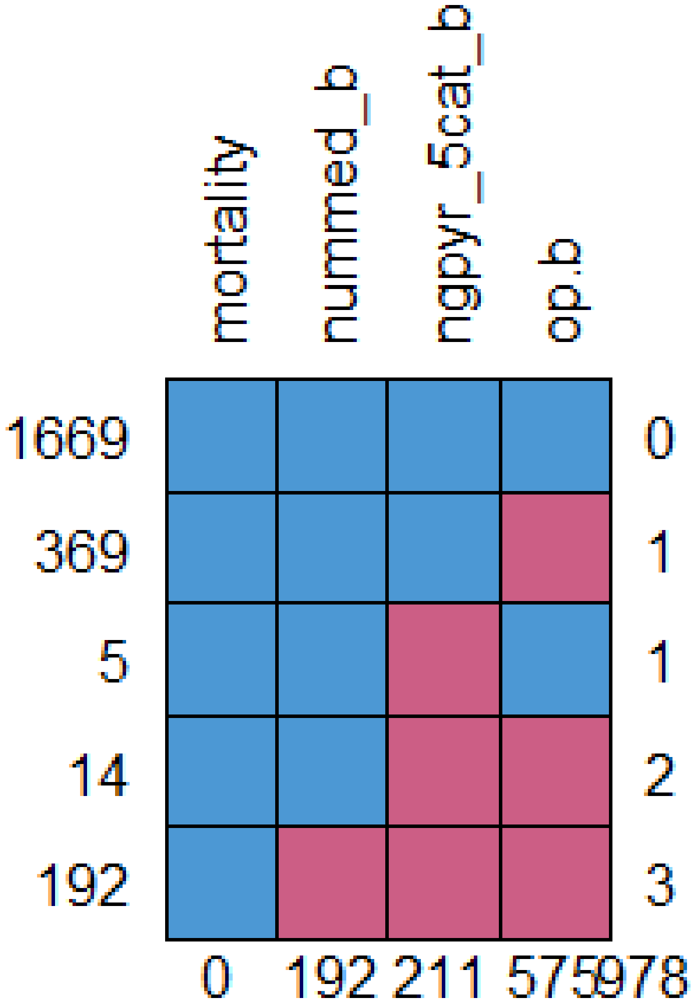


Figure A51: Figure demonstrating missingness for treatment burden variables across the cohort at wave two

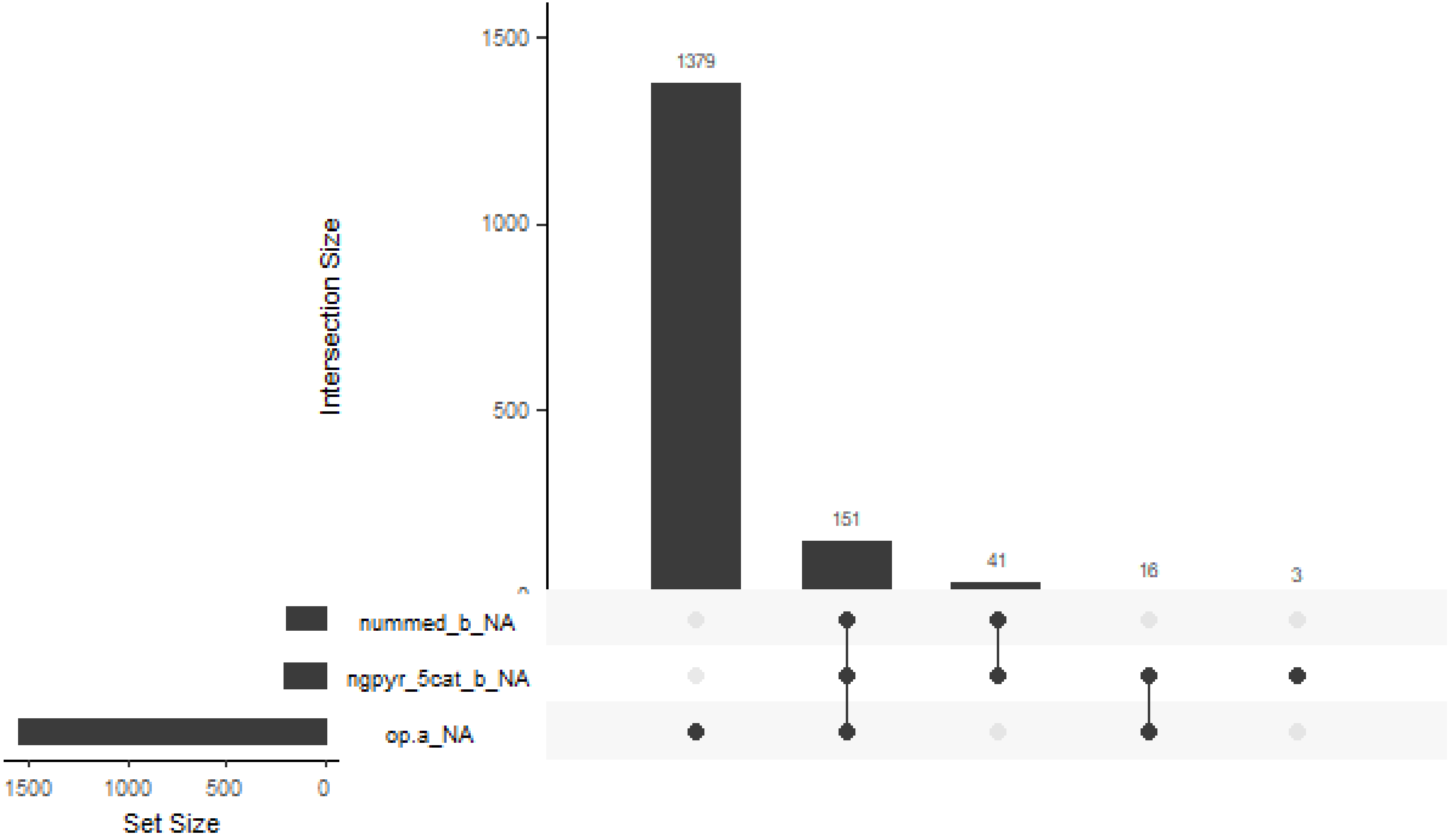


Figure A52: Figure demonstrating missingness for treatment burden variables across the cohort at wave three

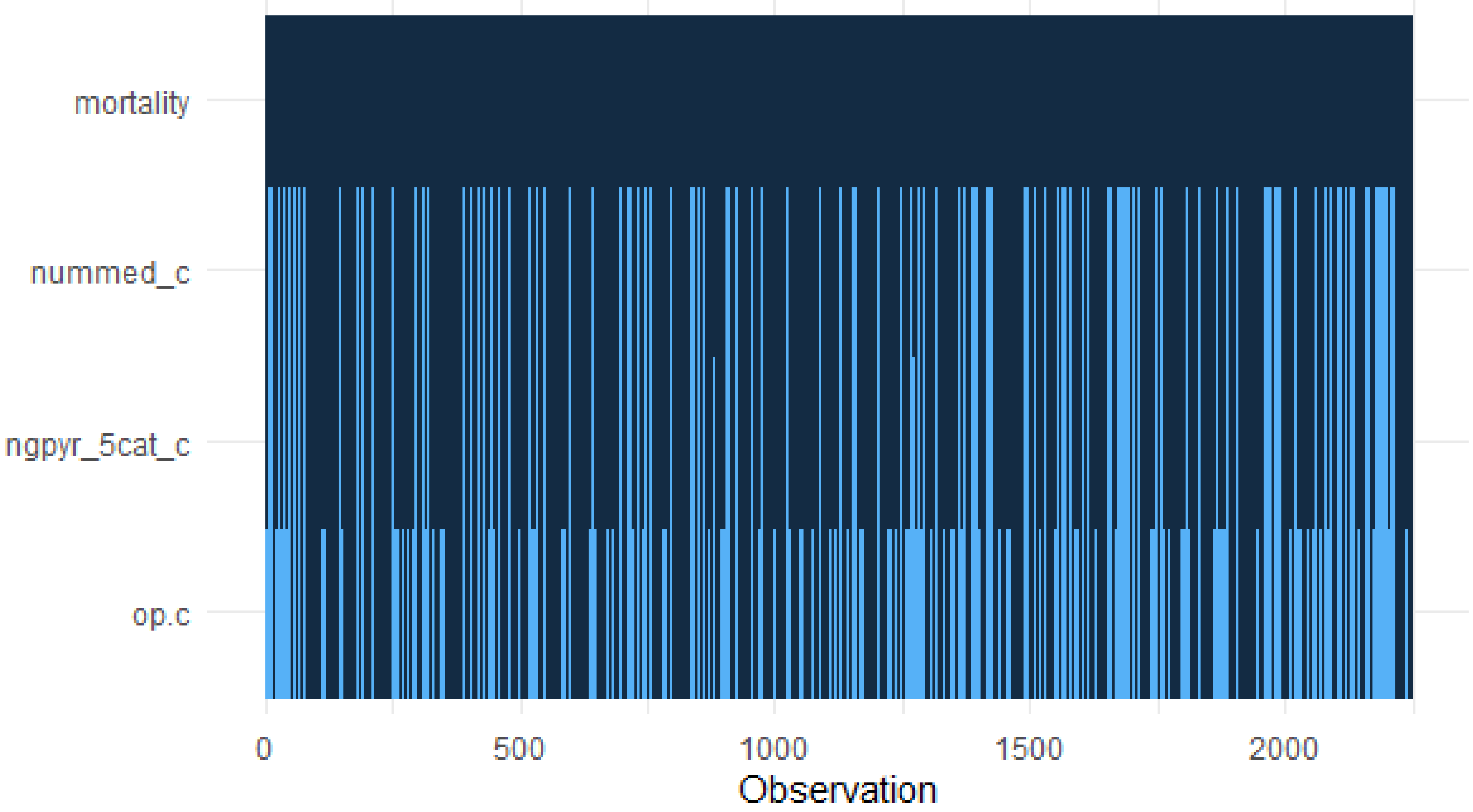


Figure A53 : Figure demonstrating missingness for treatment burden variables across the cohort at wave three

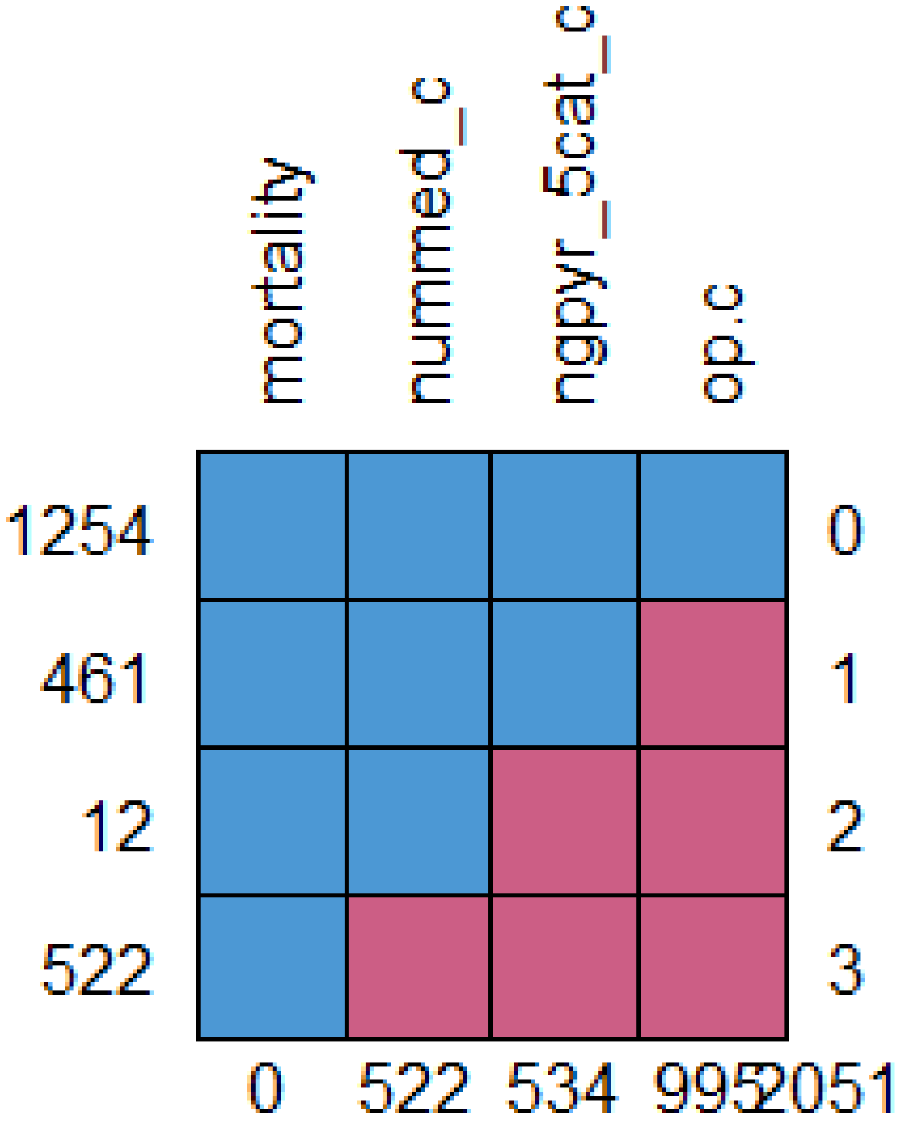


Figure A54: Figure demonstrating missingness for each treatment burden variables across the cohort at wave three

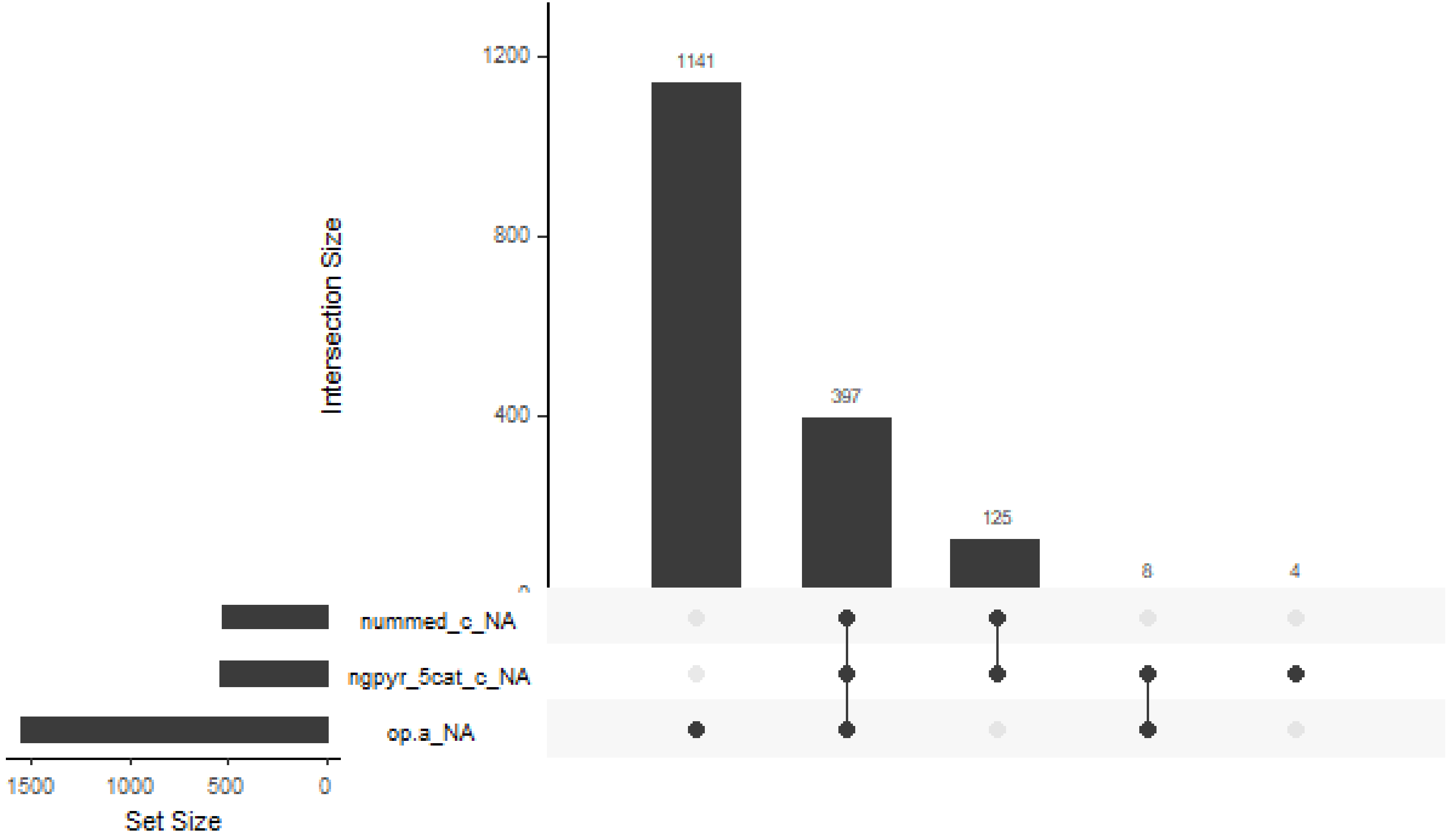


Figure A55 - Figure demonstrating missingness for treatment burden variables across the cohort at wave four

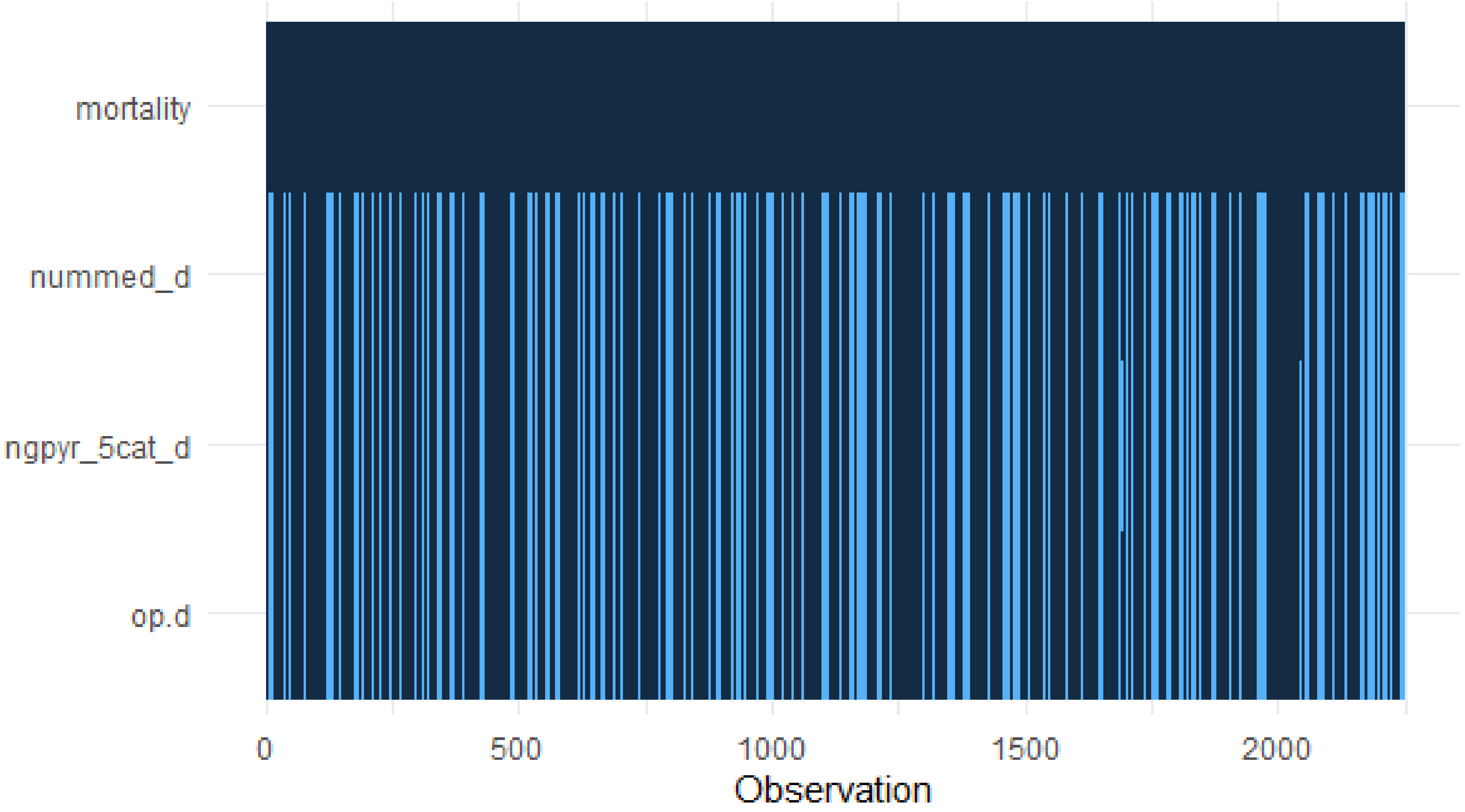


Figure A56 : Figure demonstrating missingness for treatment burden variables across the cohort at wave four

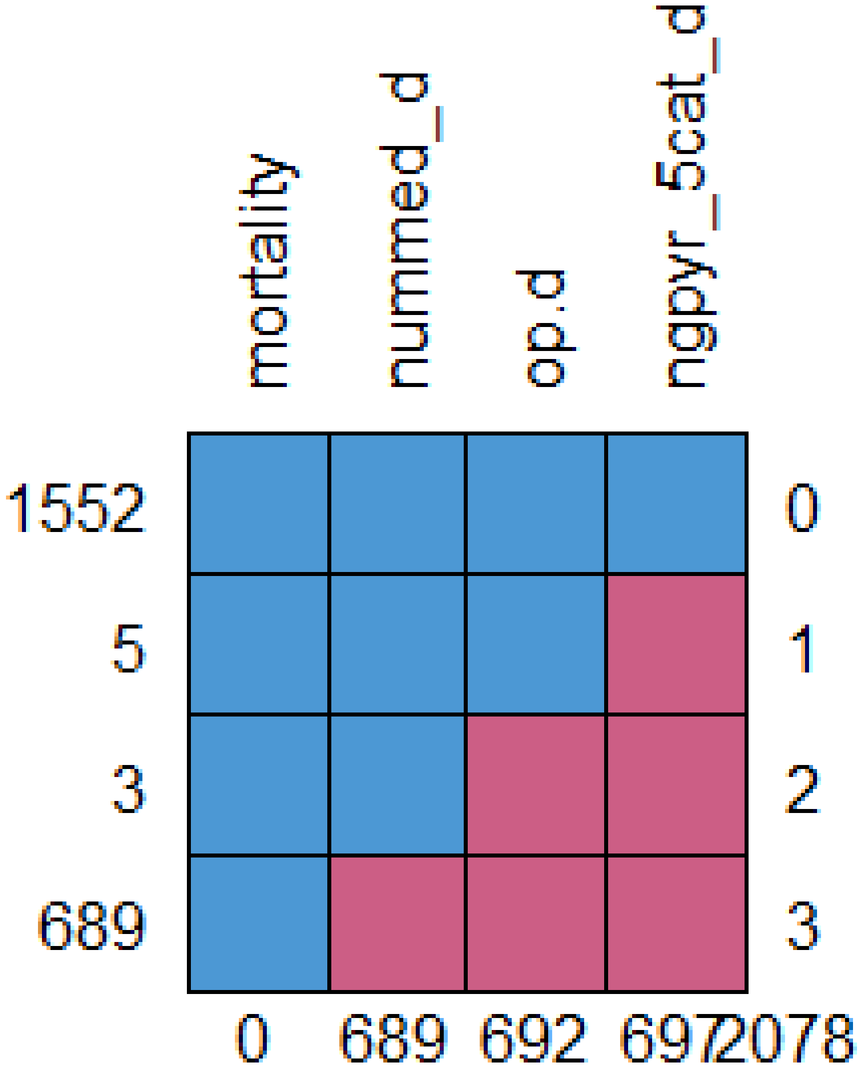


Figure A57 : Figure demonstrating missingness for treatment burden variables across the cohort at baseline

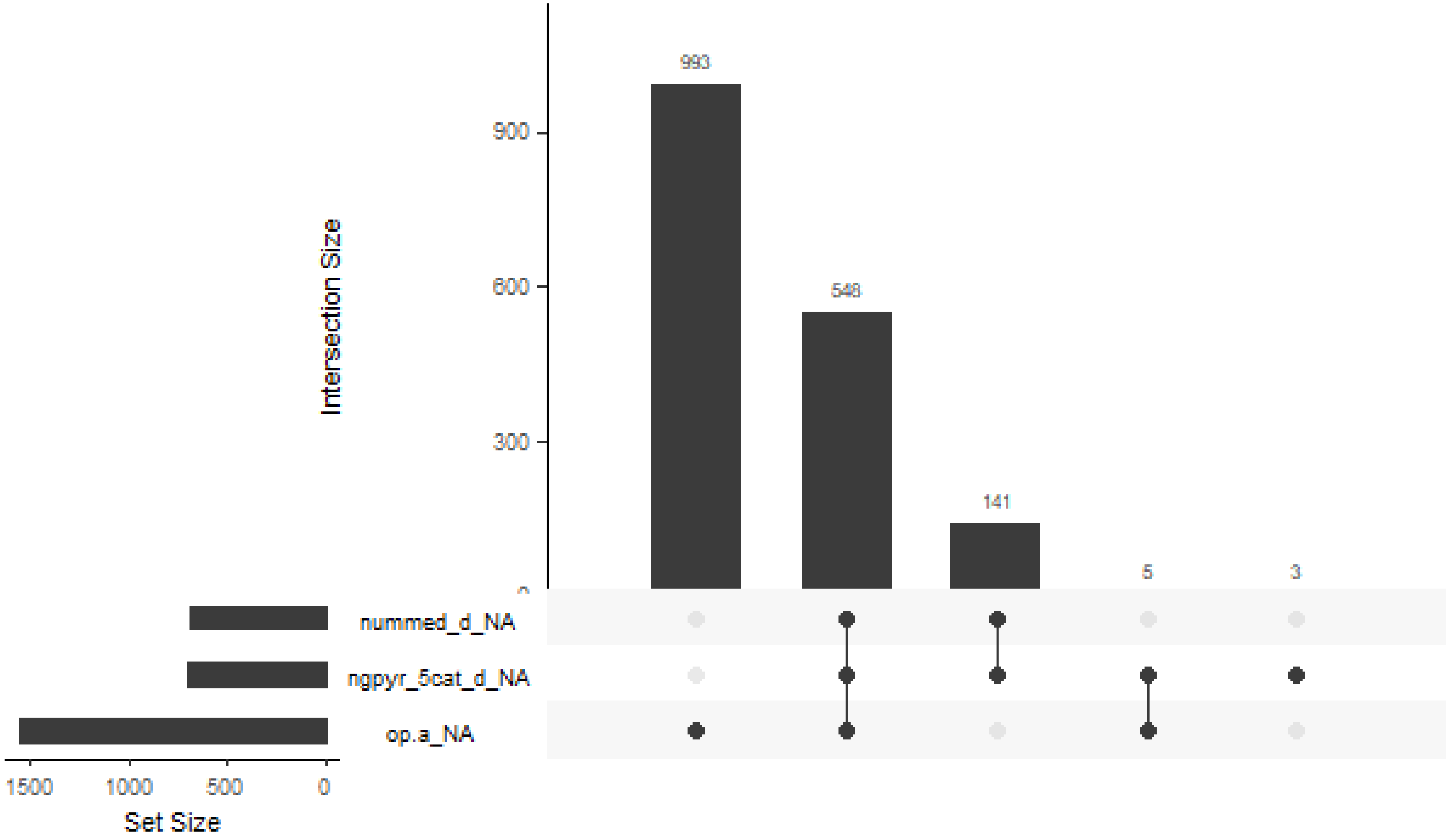


Figure A58 Figure demonstrating missingness for treatment burden variables across the cohort at wave five

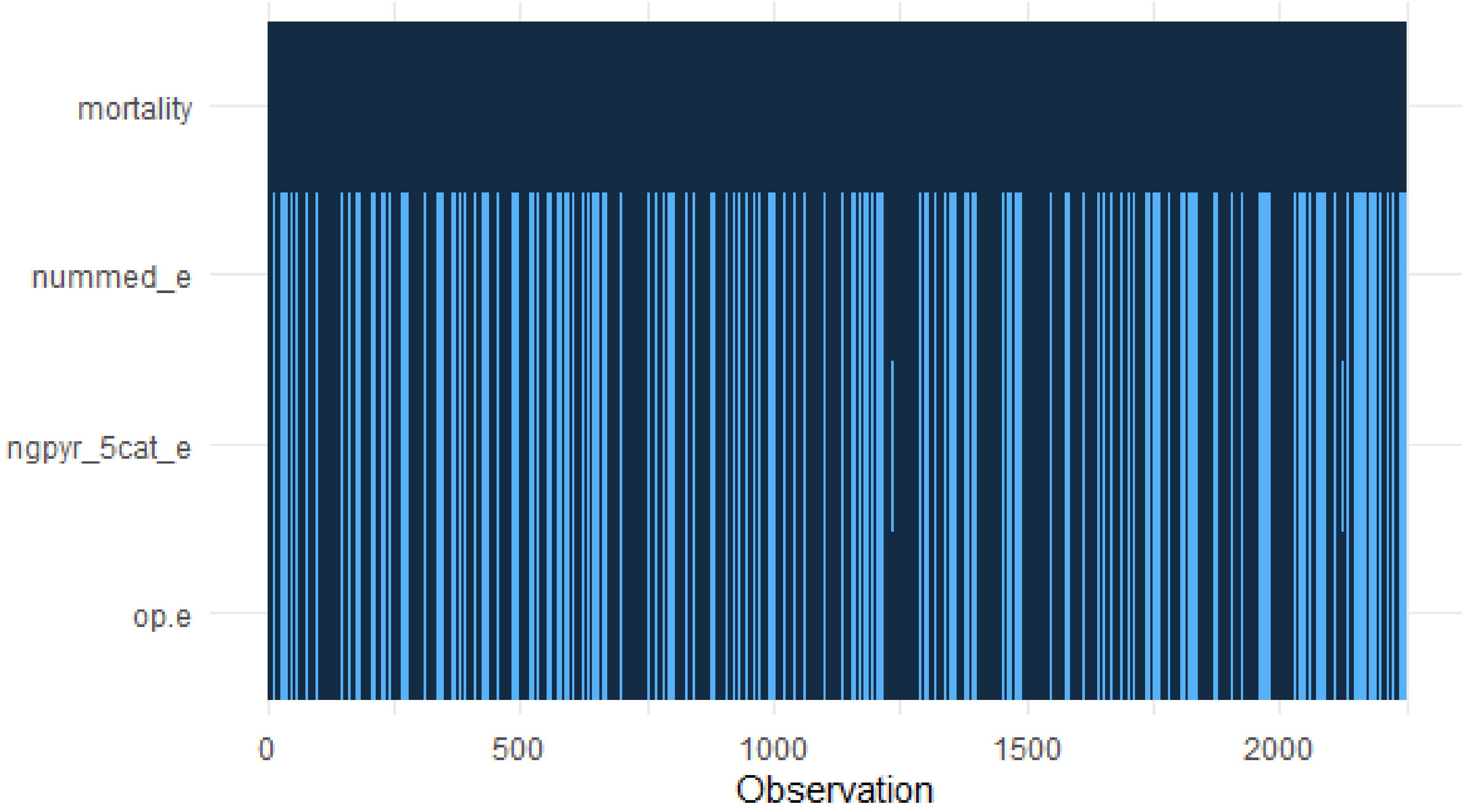


Figure A59 : Figure demonstrating missingness for treatment burden variables across the cohort at wave 5

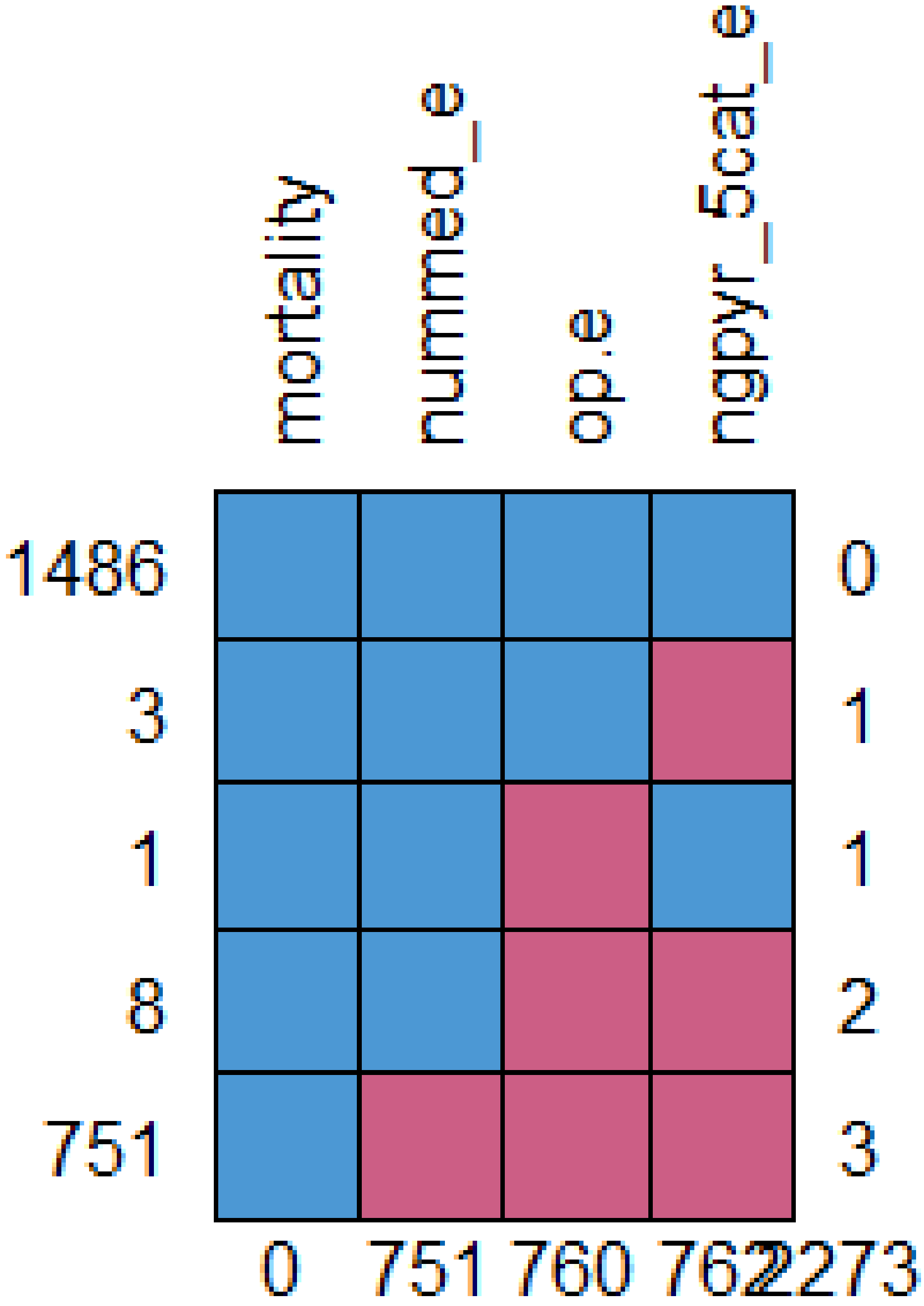
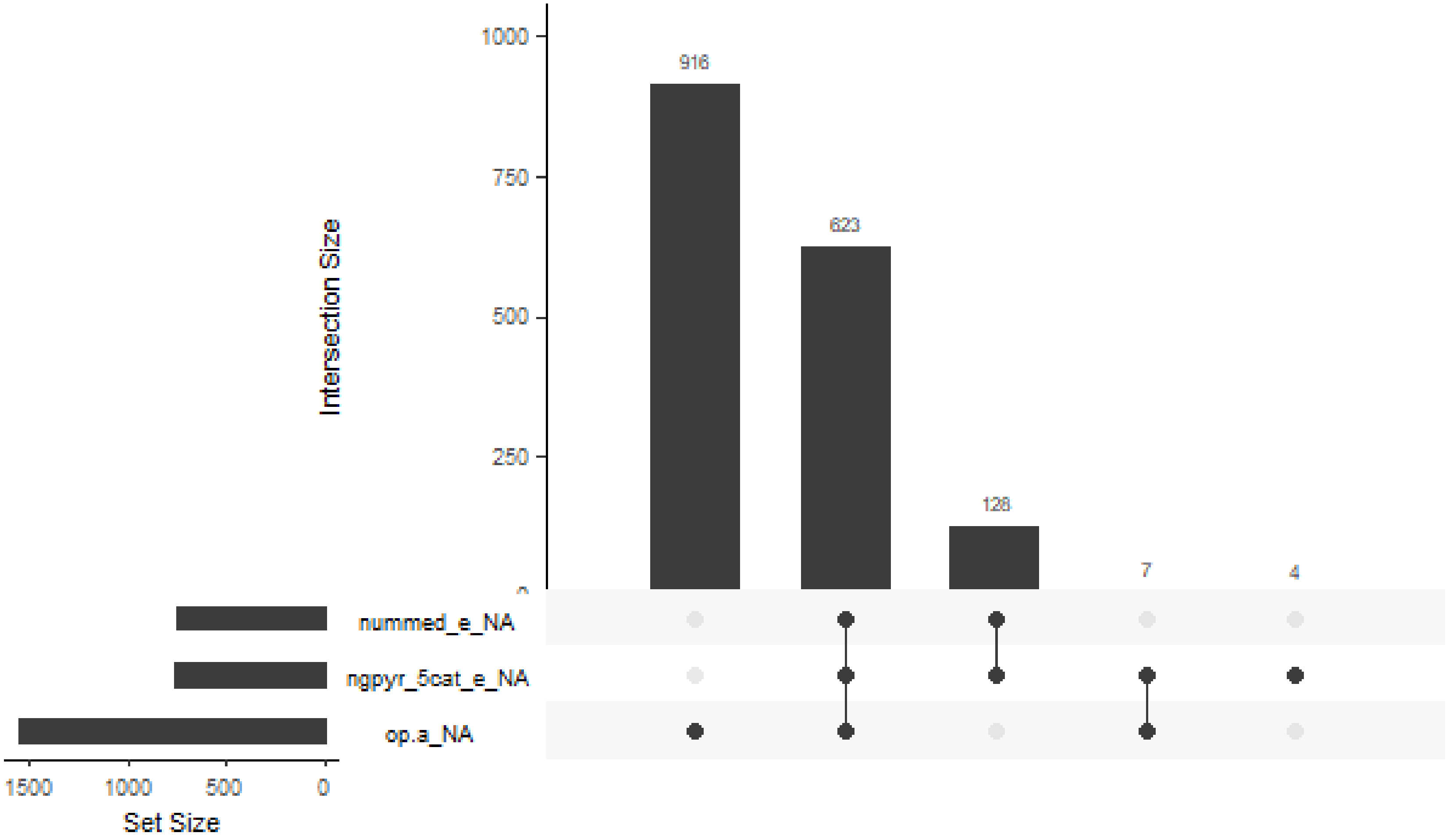


Figure A45: Figure demonstrating missingness for treatment burden variables across the cohort at wave five



Appendix 13: Sensitivity Analysis using multimorbidity as a time varying covariate

The analysis was done on a subset of the original cohort who had multimorbidity at any of the waves within the cohort. This meant at each wave there were a small number whose may not have had multimorbidity at a particular wave (because they had not developed it, or because of the self-reported nature of the variable, discussed in Chapter 9). To explore whether this influenced the findings a sensitivity analysis was conducted:

For the mortality tables:

- Model 1 is the Hazard Ratio fully adjusted for the existing confounders presented in Chapter 8
- Model 2 is the Hazard Ratio for model 1 where presence or absence of multimorbidity has been included as a time-varying covariate.

For the Hospital admission tables:

- Model 1 is the Odds Ratio fully adjusted for the existing confounders presented in Chapter 8
- Model 2 is the Odds Ratio adjusting for all the existing confounders and presence or absence of multimorbidity.

The Sensitivity analysis showed very little change in effect, or confidence interval size.

Table A15-1 Table demonstrating Hazard Ratio for Mobilising Capacity Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Hazard Ratio (Confidence Interval)	
	Model 1	Model 2
Equivalised Household Income	1 (1,1)	1 (1,1)
Housing Tenancy		
Owner	1	1
Social Housing	1.39 (1.14,1.68)**	1.39 (1.14,1.68)**
Private Rent	1.23 (0.7,2.17)	1.18 (0.67,2.09)
Other	1.28 (0.62,2.64)	1.41 (0.68,2.9)
Access to a car		

Yes	1	1
No	1.13 (0.93,1.36))	1.13 (0.94,1.37)
Employment Status		
Employed/self-employed	1	1
Full Time Education	3.70 (0.83,16.52)	3.47 (0.78,15.48)
Carer/Housewife	2.00 (1.26,3.19)**	1.96 (1.23,3.13)
Retired	1.63 (1.14,2.33)**	1.60 (1.12,2.3)
Unemployed	1.83 (0.97,3.44)	1.74 (0.92,3.29)
Disabled	2.88 (1.98,4.19)**	2.68 (1.84,3.91)
Seen Family member in the last month?		
Yes	1	1
No	1.31 (0.54,3.17)	1.31 (0.54,3.19)
Seen Friend in the last month?		
Yes	1	1
No	0.61 (0.25,1.49)	0.62 (0.25,1.52)
Number of people you can rely on for practical support		
None	1	1
Up to five	1.04 (0.76,1.43)	1.02 (0.74,1.4)
Five to ten	1.03 (0.71,1.50)	1.00 (0.69,1.45)
More than ten	1.07 (0.62,1.87)	1.05 (0.61,1.83)
Do you ever feel lonely?		
Never	1	1
Seldom	0.68 (0.51,0.91)**	0.68 (0.51,0.92)**
Occasionally	0.89 (0.71,1.12)	0.88 (0.70,1.10)
Quite often	1.74 (1.27,2.39)**	1.66 (1.21,2.28)**
Most of the time	0.93 (0.58,1.49)	0.91 (0.57,1.45)
Have you someone you can share your feelings with?		
All	1	1
Some feelings	0.79 (0.64,0.99)*	0.81 (0.65,1.01)
A few feelings	0.68 (0.48,0.95)*	0.68 (0.49,0.96)*
Have you someone you can confide in?		
Very frequently	1	1
More often than not	1.12 (0.75,1.68)	1.13 (0.75,1.69)
Occasionally	1.17 (0.80,1.70)	1.18 (0.81,1.72)
Never	1.02 (0.71,1.47)	1.04 (0.72,1.51)
Are you a carer?		
Yes	1	1
No	0.72 (0.58,0.90)*	0.72 (0.58,0.90)*
Divorced in the last year?		
Yes	1	1
No	**2.07 (1.11,3.87)**	2.13 (1.14,3.98)*
Become unemployed in the last year?		
Yes	1	1
No	0.71 (0.30,1.70)	0.71 (0.30,1.68)
Change in employment in the last year?		
Yes	1	1
No	1.2 (0.59,2.46)	1.18 (0.58,2.41))
Death in the family		
No	1	1
Yes	0.79 (0.62,1.00)	0.79 (0.63,1.00)
Death of friend in the last year?		
No	1	1
Yes	0.89 (0.71,1.12)	0.88 (0.7,1.1)

Table A15-2 Table demonstrating Odds Ratio for self-reported hospital admission for Mobilising Capacity Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)	
	Model 1	Model 2
Equivalised Household Income	1 (1,1)	1 (1,1)
Housing Tenancy		
Owner	1	1
Social Housing	1.2 (0.89,1.61)	1.19 (0.88,1.6)
Private Rent	1.3 (0.58,2.64)	1.29 (0.58,2.62)
Other	1.61 (0.44,4.63)	1.52 (0.42,4.39)
Access to a car		
Yes	1	1
No	1.00 (0.75,1.32)	1.01 (0.76,1.34)
Employment Status		
Employed/self-employed	1	1
Full Time Education	0.55 (0.03,3.02)	0.52 (0.03,2.9)
Carer/Housewife	1.74 (1.07,2.78)	1.69 (1.04,2.7)
Retired	2.43 (1.61,3.69)**	2.38 (1.58,3.61)**
Unemployed	1.12 (0.5,2.31)	1.08 (0.48,2.23)
Disabled	2.57 (1.67,3.95)**	2.44 (1.57,3.75)**
Seen Family member in the last month?		
Yes	1	1
No	0.74 (0.42,1.41)	0.72 (0.41,1.37)
Seen Friend in the last month?		
Yes	1	1
No	1.14 (0.6,2.04)	1.19 (0.62,2.13)
Number of people you can rely on for practical support		
None	1	1
Up to five	1.50 (0.88,2.72)	1.47 (0.86,2.66)
Five to ten	1.74 (0.96,3.28)	1.68 (0.93,3.17)
More than ten	1.60 (0.69,3.64)	1.57 (0.68,3.57)
Do you ever feel lonely?		
Never	1	1
Seldom	0.93 (0.62,1.35)	0.92 (0.62,1.34)
Occasionally	0.76 (0.54,1.05)	0.75 (0.54,1.05)
Quite often	1.15 (0.72,1.8)	1.11 (0.69,1.75)
Most of the time	1.31 (0.61,2.68)	1.26 (0.59,2.57)
Have you someone you can share your feelings with?		
All	1	1
Some feelings	0.85 (0.61,1.16)	0.85 (0.62,1.16)
A few feelings	0.62 (0.32,1.1)	0.62 (0.32,1.11)
Have you someone you can confide in?		
Very frequently	1	1
More often than not	1.03 (0.57,1.9)	1.03 (0.57,1.91)
Occasionally	0.72 (0.42,1.27)	0.72 (0.42,1.27)
Never	0.8 (0.47,1.39)	0.81 (0.48,1.41)
Are you a carer?		
Yes	1	1
No	0.75 (0.56,0.99)	0.76 (0.57,1)
Divorced in the last year?		
Yes	1	1
No	1.59 (0.64,3.78)	1.52 (0.61,3.63)
Become unemployed in the last year?		
Yes	1	1
No	1.05 (0.34,2.72)	1.02 (0.33,2.64)

Change in employment in the last year? Yes No	 1 0.52 (0.2,1.15)	 1 0.51 (0.19,1.13)
Death in the family No Yes	 1 0.89 (0.59,1.32)	 1 0.89 (0.59,1.3)
Death of friend in the last year? No Yes	 1 1.32 (0.92,1.85)	 1 1.26 (0.88,1.78)

Table A15-3 Table demonstrating Hazard Ratio for Expressing Capacity Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Hazard Ratio (95% Confidence interval)	
	Model 1	Model 2
Over the last 12 months would you say your health on the whole has been…… Good Fairly good Not good	 1 1.14 (0.84,1.55) 1.19 (0.77,1.83)	 1 1.12 (0.82,1.51) 1.16 (0.75,1.78)
Would you say that for someone your own age your health in general is… Excellent Good Fair Poor	 1 0.94 (0.65,1.36) 1.38 (0.89,2.16) 2.18 (1.17,4.04)**	 1 0.94 (0.65,1.36) 1.38 (0.88,2.16) 2.15 (1.16,4)**
Registered disability No Yes	 1 1.7 (1.28,2.27)**	 1 1.7 (1.27,2.26)**
Depression No Mild Moderate Severe	 1 1.04 (0.74,1.48) 0.71 (0.4,1.27) 13.43 (2.26,79.89)**	 1 1.02 (0.72,1.45) 0.70 (0.39,1.25) 12.31 (2.07,73.33)**
Anxiety No Mild Moderate Severe	 1 1.08 (0.81,1.46) 0.86 (0.57,1.28) 0.66 (0.28,1.57)	 1 1.08 (0.8,1.45) 0.86 (0.57,1.29) 0.66 (0.28,1.56)
AH4 score (literacy/numeracy)	0.97 (0.96,0.99)**	0.97 (0.96,0.99)**
Rosenburg self-esteem score	0.98 (0.94,1.02)	0.98 (0.94,1.02)
Number community clubs involved in None One Two Three Four or more	 1 1.02 (0.78,1.33) 0.78 (0.56,1.09) 1.06 (0.71,1.58) 0.96 (0.56,1.62))	 1 1.02 (0.78,1.33) 0.79 (0.57,1.1) 1.04 (0.7,1.56) 0.94 (0.55,1.59)
Not limited by LTC Limiting longstanding illness	1 1.07 (0.7,1.63) 1.28 (0.87,1.89)	
Maximum Educational Achievement by age 35 No Qualifications Standard Grades Apprenticeship Higher	 1 1.51 (1.03,2.2)** 0.96 (0.68,1.34) 1.2 (0.74,1.95)	 1 1.5 (1.02,2.19)** 0.95 (0.68,1.33) 1.2 (0.74,1.94)

HND	2.65 (1.36,5.16)**	2.59 (1.33,5.04)**
Degree	1.52 (0.98,2.36)	1.5 (0.96,2.33)
Health Locus of Control statement	Health Locus of Control statements	
I have the power to make myself well		
Agree Strongly	1	1
Agree quite a bit	1.1 (0.75,1.63)	1.11 (0.75,1.65)
Agree a little	0.68 (0.45,1.02)	0.69 (0.46,1.04)
Disagree a little	0.54 (0.33,0.9)	0.54 (0.33,0.9)
Disagree quite a bit	0.68 (0.4,1.17)	0.7 (0.41,1.2)
Disagree a lot	0.53 (0.3,0.95)	0.52 (0.29,0.93)
I have no control over being ill		
Agree Strongly	1	1
Agree quite a bit	1.02 (0.59,1.77)	0.99 (0.57,1.71)
Agree a little	1.25 (0.74,2.14)	1.24 (0.72,2.11)
Disagree a little	1.63 (0.94,2.83)	1.58 (0.91,2.74)
Disagree quite a bit	1.26 (0.74,2.14)	1.22 (0.72,2.08)
Disagree a lot	1.32 (0.81,2.16)	1.32 (0.81,2.16)
Regular doctor visits reduce health		
Agree Strongly	1	1
Agree quite a bit	1.77 (1.07,2.95)	1.77 (1.07,2.95)
Agree a little	1.08 (0.69,1.69)	1.08 (0.69,1.69)
Disagree a little	0.83 (0.48,1.41)	0.79 (0.46,1.36)
Disagree quite a bit	0.98 (0.6,1.62)	0.95 (0.58,1.56)
Disagree a lot	0.88 (0.55,1.4)	0.85 (0.53,1.36)
Accidental happening influence health		
Agree Strongly	1	1
Agree quite a bit	1.48 (0.78,2.82)	1.48 (0.78,2.81)
Agree a little	1.12 (0.62,2.02)	1.12 (0.62,2.03)
Disagree a little	1.39 (0.75,2.58)	1.4 (0.75,2.59)
Disagree quite a bit	1.26 (0.68,2.33)	1.3 (0.7,2.4)
Disagree a lot	1 (0.56,1.8)	1.02 (0.57,1.83)
Only doctors can maintain health		
Agree Strongly	1	1
Agree quite a bit	1.31 (0.71,2.43)	1.33 (0.71,2.46)
Agree a little	0.6 (0.33,1.11)	0.6 (0.32,1.11)
Disagree a little	0.74 (0.39,1.38)	0.73 (0.39,1.38)
Disagree quite a bit	0.91 (0.49,1.68)	0.91 (0.49,1.69)
Disagree a lot	1.03 (0.57,1.84)	1.03 (0.57,1.85)
I am responsible for my health		
Agree Strongly	1	1
Agree quite a bit	1.09 (0.79,1.51)	1.09 (0.79,1.51)
Agree a little	1.69 (1.14,2.51)*	1.67 (1.13,2.49)*
Disagree a little	1.59 (0.96,2.63)	1.53 (0.92,2.55)
Disagree quite a bit	1.24 (0.62,2.46)	1.25 (0.63,2.48)
Disagree a lot	0.65 (0.31,1.36)	0.69 (0.33,1.45)
Others are responsible for my health		
Agree Strongly	1	1
Agree quite a bit	1.25 (0.7,2.24)	1.27 (0.71,2.26)
Agree a little	0.85 (0.49,1.49)	0.88 (0.5,1.54)
Disagree a little	1.65 (0.92,2.94)	1.67 (0.93,2.99)
Disagree quite a bit	0.76 (0.44,1.3)	0.77 (0.44,1.32)
Disagree a lot	1.15 (0.69,1.93)	1.19 (0.71,1.99)
It’s my fault when things go wrong with my health		
Agree Strongly	1	1
Agree quite a bit	1.25 (0.76,2.05)	1.23 (0.75,2.02)
Agree a little	1.35 (0.83,2.17)	1.37 (0.85,2.21)

Disagree a little	1.33 (0.81,2.17)	1.34 (0.82,2.2)
Disagree quite a bit	1.46 (0.88,2.42)	1.47 (0.88,2.43)
Disagree a lot	1.16 (0.7,1.9)	1.16 (0.7,1.9)
When I am ill, I let nature run its course		
Agree Strongly	1	1
Agree quite a bit	1.08 (0.67,1.74)	1.06 (0.66,1.71)
Agree a little	1.05 (0.67,1.64)	1.03 (0.66,1.6)
Disagree a little	1.13 (0.68,1.88)	1.14 (0.69,1.89)
Disagree quite a bit	1.06 (0.66,1.72)	1.04 (0.64,1.68)
Disagree a lot	1.06 (0.66,1.68)	1.04 (0.65,1.65)
When I’m health it’s because I am lucky		
Agree Strongly	1	1
Agree quite a bit	0.8 (0.47,1.37)	0.79 (0.46,1.35)
Agree a little	0.93 (0.54,1.6)	0.94 (0.55,1.61)
Disagree a little	0.85 (0.49,1.49)	0.86 (0.49,1.5)
Disagree quite a bit	0.92 (0.51,1.65)	0.93 (0.52,1.68)
Disagree a lot	1.04 (0.58,1.86)	1.07 (0.59,1.92)
Wellbeing depends on taking care of yourself		
Agree Strongly	1	1
Agree quite a bit	1.02 (0.65,1.6)	1.01 (0.65,1.59)
Agree a little	1.08 (0.69,1.67)	1.09 (0.7,1.69)
Disagree a little	1.14 (0.69,1.87)	1.16 (0.7,1.91)
Disagree quite a bit	1.18 (0.73,1.92)	1.17 (0.72,1.91)
Disagree a lot	0.77 (0.47,1.26)	0.76 (0.46,1.25)
Illness means you have not cared for yourself		
Agree Strongly	1	1
Agree quite a bit	1.04 (0.76,1.43)	1.04 (0.76,1.42)
Agree a little	1.23 (0.81,1.88)	1.22 (0.8,1.86)
Disagree a little	1.76 (0.86,3.59)	1.68 (0.82,3.42)
Disagree quite a bit	0.64 (0.25,1.68)	0.64 (0.25,1.67)
Disagree a lot	1.96 (0.82,4.69)	1.95 (0.81,4.68)
Care from others helps me to get well		
Agree Strongly	1	1
Agree quite a bit	0.48 (0.32,0.72)**	0.48 (0.32,0.73)**
Agree a little	0.62 (0.41,0.94)**	0.62 (0.41,0.95)**
Disagree a little	0.4 (0.25,0.65)**	0.41 (0.25,0.66)**
Disagree quite a bit	0.53 (0.33,0.85)**	0.53 (0.33,0.86)**
Disagree a lot	0.77 (0.46,1.27)	0.76 (0.46,1.26)
Illness is luck		
Agree Strongly	1	1
Agree quite a bit	0.87 (0.58,1.29)	0.87 (0.59,1.29)
Agree a little	1.1 (0.73,1.64)	1.1 (0.74,1.64)
Disagree a little	1.45 (0.89,2.36)	1.44 (0.88,2.35)
Disagree quite a bit	0.98 (0.56,1.7)	0.99 (0.57,1.73)
Disagree a lot	0.93 (0.51,1.67)	0.93 (0.51,1.67)
Looking after myself keeps me healthy		
Agree Strongly	1	1
Agree quite a bit	0.99 (0.63,1.56)	1.02 (0.65,1.61)
Agree a little	1.24 (0.8,1.94)	1.26 (0.8,1.97)
Disagree a little	0.82 (0.49,1.35)	0.84 (0.51,1.39)
Disagree quite a bit	1.12 (0.7,1.81)	1.15 (0.72,1.85)
Disagree a lot	1.55 (0.93,2.56)	1.59 (0.96,2.63)
Doctor’s orders keep me healthy		
Agree Strongly	1	1
Agree quite a bit	0.69 (0.37,1.32)	0.72 (0.38,1.36)
Agree a little	0.72 (0.4,1.31)	0.74 (0.41,1.33)
Disagree a little	0.58 (0.31,1.06)	0.59 (0.32,1.08)

Disagree quite a bit	0.62 (0.33,1.15)	0.63 (0.34,1.17)
Disagree a lot	0.89 (0.49,1.61)	0.91 (0.5,1.66)
I can usually stay healthy by taking good care of myself		
Agree Strongly	1	1
Agree quite a bit	1.23 (0.86,1.76)	1.24 (0.86,1.77)
Agree a little	1.2 (0.79,1.83)	1.22 (0.8,1.85)
Disagree a little	1.24 (0.71,2.16)	1.29 (0.74,2.24)
Disagree quite a bit	1.57 (0.8,3.07)	1.59 (0.81,3.12)
Disagree Strongly	0.98 (0.38,2.56)	0.95 (0.36,2.46)
Following the doctors order to the letter is the way to stay healthy		
Agree Strongly	1	1
Agree quite a bit	0.8 (0.56,1.13)	0.79 (0.56,1.12)
Agree a little	1.01 (0.7,1.47)	1.01 (0.7,1.47)
Disagree a little	0.57 (0.34,0.97)	0.57 (0.34,0.96)
Disagree quite a bit	1.14 (0.67,1.95)	1.13 (0.66,1.93)
Disagree Strongly	0.53 (0.28,1)	0.53 (0.28,1.01)
I have little control over what happens to me		
Strongly agree	1	1
Agree	0.51 (0.27,0.98)	0.51 (0.27,0.98)
Disagree	0.47 (0.25,0.9)	0.47 (0.25,0.9)
Strongly disagree	0.57 (0.28,1.14)	0.55 (0.27,1.11)
There is no way I can solve some of the problems I have		
Strongly agree	1	1
Agree	0.91 (0.47,1.79)	0.93 (0.47,1.83)
Disagree	0.86 (0.43,1.74)	0.86 (0.43,1.75)
Strongly disagree	0.83 (0.38,1.82)	0.85 (0.39,1.86)
There is little I can do to change many of the important things in my life		
Strongly agree	1	1
Agree	0.61 (0.29,1.27)	0.6 (0.29,1.25)
Disagree	0.56 (0.26,1.19)	0.54 (0.25,1.16)
Strongly disagree	0.49 (0.21,1.16)	0.47 (0.2,1.12)
Sometimes I feel helpless dealing with the problems in life		
Strongly agree	1	1
Agree	1.13 (0.54,2.37)	1.12 (0.54,2.36)
Disagree	1.22 (0.56,2.65)	1.22 (0.56,2.65)
Strongly disagree	1.08 (0.47,2.47)	1.08 (0.47,2.48)
Sometimes I feel I am pushed around in life		
Strongly agree	1	1
Agree	0.88 (0.4,1.94)	0.89 (0.41,1.94)
Disagree	1.38 (0.63,3.04)	1.42 (0.65,3.11)
Strongly disagree	1.19 (0.51,2.79)	1.21 (0.52,2.84)
What happens in the future depends mostly on me		
Strongly agree	1	1
Agree	1 (0.67,1.49)	1.01 (0.68,1.51)
Disagree	1.16 (0.72,1.88)	1.16 (0.72,1.88)
Strongly disagree	0.55 (0.27,1.11)	0.55 (0.27,1.11)
I can do just about anything I set my mind to		
Strongly agree	1	1
Agree	1 (0.65,1.53)	1 (0.65,1.54)
Disagree	0.82 (0.49,1.37)	0.83 (0.5,1.39)
Strongly disagree	1.28 (0.59,2.76)	1.27 (0.59,2.74)

Table A15-4 Table demonstrating Odds Ratio for self-reported hospital admission for Expressing Capacity Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)	
	Model 1	Model 2
Over the last 12 months would you say your health on the whole has been……		
Good	1	1
Fairly good	2.82 (1.94,4.1)**	2.71 (1.86,3.93)**
Not good	7.92 (4.64,13.54)**	7.39 (4.33,12.66)**
Would you say that for someone your own age your health in general is…		
Excellent	1	1
Good	0.78 (0.51,1.2)	0.76 (0.5,1.17)
Fair	0.66 (0.38,1.16)	0.64 (0.36,1.11)
Poor	0.78 (0.37,1.64)	0.75 (0.35,1.58)
Registered disability		
No	1	1
Yes	2.00 (1.34,2.97)**	1.97 (1.32,2.93)**
Depression		
No	1	1
Mild	1.1 (0.71,1.68)	1.08 (0.7,1.66)
Moderate	1.32 (0.69,2.51)	1.32 (0.68,2.5)
Severe	2.47 (0.07,51.52)	2.31 (0.07,45.81)
Anxiety		
No	1	1
Mild	1.00 (0.7,1.41)	0.98 (0.69,1.38)
Moderate	0.79 (0.5,1.23)	0.78 (0.49,1.22)
Severe	1.08 (0.49,2.3)	1.01 (0.46,2.15)
AH4 score (literacy/numeracy)	0.98 (0.97,1)	0.98 (0.97,1)
Rosenburg self-esteem score	1 (0.96,1.05)	1 (0.96,1.05)
Number community clubs involved in		
None	1	1
One	0.95 (0.69,1.32)	0.94 (0.68,1.3)
Two	1.46 (1,2.11)*	1.47 (1.01,2.13)*
Three	0.87 (0.5,1.44)	0.84 (0.49,1.41)
Four or more	1.45 (0.81,2.53)	1.45 (0.81,2.53)
Not limited by LTC	1	1
Limiting longstanding illness	1.1 (0.82,1.48)	1 (0.73,1.35)
Maximum Educational Achievement by age 35		
No Qualifications	1	1
Standard Grades	1.36 (0.89,2.05)	1.33 (0.87,2.01)
Apprenticeship	1.35 (0.89,2.04)	1.34 (0.88,2.02)
Higher	1.08 (0.6,1.89)	1.05 (0.58,1.84)
HND	1.68 (0.76,3.52)	1.58 (0.71,3.32)
Degree	0.94 (0.56,1.58)	0.89 (0.52,1.5)
Health Locus of Control statement		
I have the power to make myself well		
Agree Strongly	1	1
Agree quite a bit	0.97 (0.61,1.57)	0.99 (0.62,1.6)
Agree a little	0.75 (0.46,1.22)	0.77 (0.47,1.26)
Disagree a little	0.97 (0.55,1.73)	0.97 (0.55,1.73)
Disagree quite a bit	0.82 (0.42,1.59)	0.83 (0.42,1.61)
Disagree a lot	0.75 (0.37,1.49)	0.76 (0.37,1.5)

I have no control over being ill		
Agree Strongly	1	1
Agree quite a bit	0.87 (0.45,1.68)	0.85 (0.44,1.66)
Agree a little	0.78 (0.41,1.5)	0.77 (0.41,1.49)
Disagree a little	1.07 (0.55,2.09)	1.06 (0.55,2.07)
Disagree quite a bit	0.49 (0.25,0.95)*	0.48 (0.25,0.94)*
Disagree a lot	0.75 (0.41,1.39)	0.75 (0.41,1.39)
Regular doctor visits reduce health		
Agree Strongly	1	1
Agree quite a bit	1.74 (0.88,3.5)	1.7 (0.86,3.41)
Agree a little	1.57 (0.83,3.06)	1.56 (0.82,3.03)
Disagree a little	0.93 (0.46,1.93)	0.92 (0.45,1.9)
Disagree quite a bit	1.17 (0.59,2.35)	1.16 (0.59,2.34)
Disagree a lot	1.28 (0.67,2.5)	1.29 (0.67,2.51)
Accidental happening influence health		
Agree Strongly	1	1
Agree quite a bit	1.35 (0.63,2.99)	1.33 (0.62,2.94)
Agree a little	0.93 (0.46,1.95)	0.91 (0.45,1.91)
Disagree a little	1.21 (0.58,2.57)	1.18 (0.57,2.51)
Disagree quite a bit	1.01 (0.49,2.16)	1.01 (0.49,2.15)
Disagree a lot	1.7 (0.86,3.51)	1.68 (0.84,3.47)
Only doctors can maintain health		
Agree Strongly	1	1
Agree quite a bit	1.3 (0.57,2.98)	1.32 (0.58,3.05)
Agree a little	0.96 (0.43,2.17)	0.95 (0.42,2.16)
Disagree a little	1.9 (0.88,4.19)	1.9 (0.88,4.19)
Disagree quite a bit	1.93 (0.91,4.18)	1.91 (0.9,4.16)
Disagree a lot	1.72 (0.83,3.66)	1.66 (0.8,3.54)
I am responsible for my health		
Agree Strongly	1	1
Agree quite a bit	1.08 (0.74,1.58)	1.09 (0.75,1.6)
Agree a little	1.25 (0.79,1.98)	1.25 (0.79,1.97)
Disagree a little	0.5 (0.24,0.98)	0.48 (0.23,0.95)
Disagree quite a bit	1.41 (0.64,2.97)	1.39 (0.63,2.95)
Disagree a lot	0.77 (0.31,1.8)	0.79 (0.32,1.86)
Others are responsible for my health		
Agree Strongly	1	1
Agree quite a bit	1.8 (0.85,3.89)	1.78 (0.84,3.85)
Agree a little	1.72 (0.85,3.6)	1.75 (0.86,3.67)
Disagree a little	1.97 (0.94,4.24)	1.97 (0.94,4.23)
Disagree quite a bit	1.54 (0.76,3.23)	1.58 (0.78,3.3)
Disagree a lot	1.7 (0.88,3.4)	1.75 (0.91,3.5)
It’s my fault when things go wrong with my health		
Agree Strongly	1	1
Agree quite a bit	0.74 (0.4,1.37)	0.71 (0.38,1.33)
Agree a little	0.89 (0.49,1.61)	0.87 (0.48,1.58)
Disagree a little	0.75 (0.4,1.39)	0.73 (0.39,1.36)
Disagree quite a bit	1.23 (0.68,2.24)	1.21 (0.67,2.21)
Disagree a lot	0.85 (0.46,1.57)	0.83 (0.45,1.52)
When I am ill, I let nature run its course		
Agree Strongly	1	1
Agree quite a bit	0.68 (0.38,1.23)	0.67 (0.37,1.21)
Agree a little	1.09 (0.64,1.89)	1.07 (0.63,1.86)
Disagree a little	1.15 (0.63,2.1)	1.15 (0.63,2.1)
Disagree quite a bit	0.95 (0.53,1.69)	0.94 (0.53,1.68)
Disagree a lot	1.08 (0.61,1.91)	1.07 (0.61,1.89)

When I'm health it's because I am lucky		
Agree Strongly	1	1
Agree quite a bit	0.71 (0.34,1.46)	0.7 (0.34,1.45)
Agree a little	0.67 (0.33,1.38)	0.68 (0.34,1.39)
Disagree a little	0.51 (0.25,1.08)	0.52 (0.25,1.1)
Disagree quite a bit	0.59 (0.29,1.24)	0.6 (0.29,1.26)
Disagree a lot	0.63 (0.3,1.33)	0.65 (0.31,1.37)
Wellbeing depends on taking care of yourself		
Agree Strongly	1	1
Agree quite a bit	1.21 (0.68,2.16)	1.21 (0.68,2.18)
Agree a little	0.93 (0.53,1.67)	0.94 (0.53,1.68)
Disagree a little	1.16 (0.62,2.19)	1.16 (0.61,2.2)
Disagree quite a bit	0.96 (0.52,1.78)	0.93 (0.51,1.74)
Disagree a lot	1.06 (0.57,1.96)	1.05 (0.57,1.95)
Illness means you have not cared for yourself		
Agree Strongly	1	1
Agree quite a bit	1.05 (0.73,1.51)	1.05 (0.73,1.51)
Agree a little	1.42 (0.86,2.32)	1.42 (0.86,2.33)
Disagree a little	1.03 (0.37,2.61)	1.02 (0.37,2.56)
Disagree quite a bit	0.64 (0.2,1.81)	0.63 (0.2,1.81)
Disagree a lot	1.37 (0.35,4.41)	1.37 (0.35,4.43)
Care from others helps me to get well		
Agree Strongly	1	1
Agree quite a bit	0.68 (0.4,1.16)	0.69 (0.41,1.19)
Agree a little	1.09 (0.65,1.85)	1.12 (0.66,1.89)
Disagree a little	0.82 (0.47,1.43)	0.85 (0.49,1.5)
Disagree quite a bit	0.78 (0.43,1.41)	0.82 (0.45,1.48)
Disagree a lot	0.98 (0.53,1.82)	1.01 (0.54,1.87)
Illness is luck		
Agree Strongly	1	1
Agree quite a bit	1.08 (0.66,1.78)	1.07 (0.65,1.76)
Agree a little	0.8 (0.49,1.34)	0.79 (0.48,1.33)
Disagree a little	0.73 (0.4,1.34)	0.72 (0.39,1.32)
Disagree quite a bit	0.97 (0.51,1.84)	0.95 (0.49,1.81)
Disagree a lot	1.07 (0.52,2.18)	1.04 (0.5,2.12)
Looking after myself keeps me healthy		
Agree Strongly	1	1
Agree quite a bit	0.9 (0.53,1.54)	0.92 (0.54,1.59)
Agree a little	1.12 (0.65,1.94)	1.13 (0.65,1.96)
Disagree a little	0.84 (0.46,1.52)	0.87 (0.48,1.59)
Disagree quite a bit	1.03 (0.59,1.83)	1.09 (0.61,1.94)
Disagree a lot	0.86 (0.46,1.59)	0.88 (0.47,1.63)
Doctor's orders keep me healthy		
Agree Strongly	1	1
Agree quite a bit	0.69 (0.31,1.55)	0.7 (0.32,1.59)
Agree a little	0.83 (0.4,1.76)	0.84 (0.41,1.8)
Disagree a little	0.96 (0.46,2.08)	0.95 (0.45,2.06)
Disagree quite a bit	0.87 (0.41,1.87)	0.86 (0.41,1.87)
Disagree a lot	0.85 (0.41,1.82)	0.87 (0.42,1.86)
I can usually stay healthy by taking good care of myself		
Agree Strongly	1	1
Agree quite a bit	1.11 (0.73,1.68)	1.1 (0.73,1.67)
Agree a little	0.88 (0.53,1.45)	0.88 (0.53,1.47)
Disagree a little	0.95 (0.48,1.87)	0.95 (0.47,1.87)
Disagree quite a bit	0.88 (0.37,2.01)	0.85 (0.35,1.96)
Disagree Strongly	0.51 (0.13,1.75)	0.48 (0.12,1.67)

Following the doctors order to the letter is the way to stay healthy		
Agree Strongly	1	1
Agree quite a bit	0.99 (0.65,1.51)	0.98 (0.64,1.49)
Agree a little	0.79 (0.5,1.25)	0.79 (0.5,1.25)
Disagree a little	1.04 (0.59,1.81)	1.01 (0.57,1.76)
Disagree quite a bit	0.78 (0.41,1.45)	0.79 (0.41,1.47)
Disagree Strongly	0.54 (0.24,1.17)	0.53 (0.24,1.15)
I have little control over what happens to me		
Strongly agree	1	1
Agree	1.96 (0.77,5.39)	2 (0.79,5.49)
Disagree	2 (0.79,5.53)	2.05 (0.81,5.67)
Strongly disagree	1.4 (0.53,4.08)	1.41 (0.53,4.1)
There is no way I can solve some of the problems I have		
Strongly agree	1	1
Agree	0.84 (0.37,1.98)	0.85 (0.37,2.01)
Disagree	0.63 (0.27,1.52)	0.63 (0.27,1.54)
Strongly disagree	0.54 (0.21,1.45)	0.55 (0.21,1.46)
There is little I can do to change many of the important things in my life		
Strongly agree	1	1
Agree	0.51 (0.21,1.28)	0.55 (0.23,1.39)
Disagree	0.57 (0.23,1.48)	0.6 (0.24,1.58)
Strongly disagree	0.58 (0.21,1.66)	0.61 (0.22,1.76)
Sometimes I feel helpless dealing with the problems in life		
Strongly agree	1	1
Agree	2.39 (0.88,7)	2.25 (0.83,6.57)
Disagree	3.17 (1.13,9.64)**	3.03 (1.09,9.19)**
Strongly disagree	3.36 (1.12,10.9)**	3.17 (1.06,10.22)**
Sometimes I feel I am pushed around in life		
Strongly agree	1	1
Agree	0.67 (0.29,1.66)	0.7 (0.3,1.76)
Disagree	0.63 (0.27,1.56)	0.67 (0.29,1.67)
Strongly disagree	0.7 (0.27,1.87)	0.75 (0.29,2.02)
What happens in the future depends mostly on me		
Strongly agree	1	1
Agree	0.67 (0.44,1.05)	0.66 (0.42,1.03)
Disagree	0.47 (0.27,0.81)	0.46 (0.26,0.79)
Strongly disagree	0.66 (0.28,1.49)	0.64 (0.27,1.45)
I can do just about anything I set my mind to		
Strongly agree	1	1
Agree	0.87 (0.53,1.42)	0.88 (0.54,1.45)
Disagree	0.95 (0.53,1.73)	0.96 (0.53,1.75)
Strongly disagree	1.36 (0.52,3.47)	1.36 (0.52,3.47)

Table A15-5 Table demonstrating Hazard Ratio for Community Capacity Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Hazard ratio for mortality (95% Confidence interval).	
	Model 1	Model 2
Exchange Small Favours with those who live nearby		
Yes	1	1
No	1.03 (0.88,1.21)	1.02 (0.87,1.2)
How do you feel about the area you live in (faces scale)		
1 Most Positive	1	1
2	0.86 (0.73,1.02)	0.84 (0.71,0.99)*
3	0.91 (0.75,1.1)	0.9 (0.74,1.09)
4	1.03 (0.78,1.35)	0.98 (0.75,1.29)
5	0.76 (0.48,1.21)	0.69 (0.44,1.09)
6	1.18 (0.72,1.92)	1.13 (0.69,1.83)
7 Most Negative	1.58 (1.04,2.39)	1.47 (0.97,2.23)
How do you feel about walking around the area after dark? Would you say that you		
Never	1	1
Try to avoid	0.7 (0.57,0.87)	0.73 (0.59,0.9)
Feel uncomfortable	0.66 (0.52,0.84)	0.7 (0.55,0.89)
Have no worries	0.63 (0.53,0.76)	0.65 (0.54,0.78)
Around the area you live would you say vandalism is a problem?		
Serious Problem	1	1
Minor Problem	1.03 (0.82,1.3)	0.98 (0.78,1.23)
No Problem	1.01 (0.78,1.3)	0.97 (0.75,1.24)
Around the area you live would you say litter is a problem?		
Serious Problem	1	1
Minor Problem	1.01 (0.83,1.24)	1.01 (0.83,1.23)
No Problem	1.12 (0.9,1.39)	1.11 (0.9,1.38)
Around the area you live would you say assaults are a problem?		
Serious Problem	1	1
Minor Problem	0.98 (0.74,1.29)	0.98 (0.74,1.29)
No Problem	0.92 (0.7,1.21)	0.91 (0.69,1.2)
Around the area you live would you say burglaries are a problem?		
Serious Problem	1	1
Minor Problem	0.93 (0.75,1.16)	0.96 (0.77,1.19)
No Problem	1.05 (0.84,1.31)	1.06 (0.85,1.33)
Around the area you live would you say young people causing disturbances are a problem?		
Serious Problem	1	1
Minor Problem	1.01 (0.77,1.32)	1.05 (0.8,1.38)
No Problem	0.98 (0.75,1.29)	1.03 (0.78,1.35)

Table A15-6 Table demonstrating Odds Ratio for self-reported hospital admission for Mobilising Capacity Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)	
	Model 1	Model 2
Exchange Small Favours with those who live nearby		
Yes	1	1
No	0.96 (0.79,1.16)	0.96 (0.79,1.16)
How do you feel about the area you live in (faces scale)		
1 Most Positive	1	1
2	1.17 (0.95,1.43)	1.15 (0.94,1.42)
3	1.25 (0.99,1.58)	1.24 (0.98,1.57)
4	1.01 (0.7,1.44)	0.97 (0.67,1.38)
5	1.00 (0.58,1.65)	0.93 (0.53,1.53)
6	1.96 (1.09,3.39)*	1.86 (1.03,3.23)*
7 Most Negative	1.18 (0.64,2.08)	1.14 (0.62,2.02)
How do you feel about walking around the area after dark? Would you say that you		
Never	1	1
Try to avoid	0.80 (0.6,1.05)	0.84 (0.64,1.11)
Feel uncomfortable	0.61 (0.45,0.83)**	0.64 (0.47,0.87)**
Have no worries	0.71 (0.55,0.91)**	0.75 (0.59,0.96)*
Around the area you live would you say vandalism is a problem?		
Serious Problem	1	1
Minor Problem	0.96 (0.73,1.27)	0.95 (0.72,1.26)
No Problem	0.99 (0.73,1.35)	0.98 (0.72,1.34)
Around the area you live would you say litter is a problem?		
Serious Problem	1	1
Minor Problem	1.01 (0.79,1.3)	0.98 (0.77,1.26)
No Problem	1.17 (0.9,1.53)	1.13 (0.87,1.48)
Around the area you live would you say assaults are a problem?		
Serious Problem	1	1
Minor Problem	0.63 (0.45,0.87)**	0.66 (0.47,0.92)**
No Problem	0.63 (0.45,0.87)**	0.67 (0.48,0.93)**
Around the area you live would you say burglaries are a problem?		
Serious Problem	1	1
Minor Problem	1.14 (0.9,1.45)	1.10 (0.86,1.4)
No Problem	1.26 (0.98,1.62)	1.20 (0.94,1.55)
Around the area you live would you say young people causing disturbances are a problem?		
Serious Problem	1	1
Minor Problem	1.20 (0.86,1.69)	1.21 (0.86,1.71)
No Problem	1.02 (0.73,1.44)	1.05 (0.75,1.48)

Table A15-7 Table demonstrating Hazard Ratio for Treatment Burden Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Hazard ratio for mortality (95% Confidence Interval)	
	Model 1	Model 2
Self-reported number of GP visits in the last year		
None	1	1
One	1.01 (0.75,1.35)	0.97 (0.72,1.3)
Two	0.91 (0.68,1.21)	0.86 (0.64,1.14)
Three to Five	0.99 (0.77,1.27)	0.9 (0.7,1.15)
More than Six	1.24 (0.97,1.59)	1.14 (0.89,1.46)
Self-reported number of hospital outpatient visits in the last year		
None	1	1
One	0.93 (0.67,1.29)	0.84 (0.6,1.16)
Two	0.92 (0.66,1.29)	0.81 (0.58,1.14)
Three	1.01 (0.7,1.46)	0.92 (0.63,1.32)
Four or more	1.20 (0.9,1.61)	1.08 (0.81,1.45)
Number of medications	1.09 (1.06,1.11)**	1.07 (1.05,1.09)**

Table A15-8 Table demonstrating Odds Ratio for self-reported hospital admission for Mobilising Capacity Variables when not adjusting (Model 1) or adjusting (Model 2) for presence of absence of multimorbidity.

Variables	Odds Ratio for self-reported hospital admission in the last year (95% Confidence Interval)	
	Model 1	Model 2
Self-reported number of GP visits in the last year		
None	1	1
One	1.64 (1.04,2.63)	1.64 (1.04,2.63)
Two	2.02 (1.32,3.17)	2.02 (1.32,3.18)
Three to Five	3.29 (2.24,4.99)	3.30 (2.25,5.01)
More than Six	6.00 (4.1,9.09)	6.03 (4.12,9.14)
Self-reported number of hospital outpatient visits in the last year		
None	1	1
One	4.27 (2.69,7.06)	4.28 (2.7,7.08)
Two	6.86 (4.34,11.3)	6.88 (4.35,11.34)
Three	9.02 (5.58,15.17)	9.04 (5.59,15.2)
Four or more	6.64 (4.36,10.63)	6.66 (4.37,10.67)
Number of medications	1.08 (1.06,1.11)	1.08 (1.06,1.11)

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