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EXPRESSO: EXploring the PREvalence, Service utilisation and patient experience of Severe Obesity

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Thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy (PhD)

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Abstract

Background

The study's genesis is the author's district nursing role caring for increasing numbers of individuals at home with severe obesity (BMI ≥40 kg/m^2). Such individuals often experience physical disability and functional limitations associated with severe obesity, needing help at home from community health and social care services. Care needs can pose previously unknown challenges for care providers. Little evidence exists to guide quality of care, service development or effective use of resources.

Aim

To better characterise the population with BMI ≥40 kg/m^2 who require help at home from community health and social care services.

Key questions are:

1. How many people known to health and social care services have a current BMI ≥40 kg/m^2?
2. How many of these are known to be housebound or in care?
3. What health and social care services does the BMI ≥40 kg/m^2 population use?
4. What are the costs of these health and social care services?
5. What are participants' experiences of using these services?

Methods

A scoping review of international measured prevalence data on adult BMI ≥40 kg/m^2 applied a broad search strategy, utilising diverse sources.

An instrumental case study approach was used to explore the approvals process for this mixed-methods, observational study, engaging routinely-collected data.

In a representative United Kingdom local authority, consenting individuals with severe obesity were recruited via community health and social care professionals. Participants were visited at home by the investigator, where height and weight measures were taken using specialist weighing scales and alternative height measures where needed.

An investigator-administered questionnaire recorded participants' self-reported need for help at home, including use of community health and social care services. Data were verified against routinely-collected data in health and social care records. Local and published sources informed a detailed micro-costing. Community services were also asked to identify eligible adults in a "census" of their caseloads.

A nested qualitative element involved participants undertaking individual, audio-recorded, semi-structured interviews, which were transcribed and analysed using reflexive thematic analysis.

Results

Eighteen countries, across five continents, reported BMI ≥40 kg/m^2 prevalence data in surveys since 2010: 11% of eligible national surveys examined. Prevalence of BMI ≥40 kg/m^2 ranged from 1.3% (Spain) to 7.7% (USA) for all adults, 0.7% (Serbia) to 5.6% (USA) for men and 1.8% (Poland) to 9.7% (USA) for women. Limited trend data covering recent decades support significant growth of the population with BMI ≥40 kg/m^2.

Formal approvals by nine separate stakeholders from four different organisations took nearly three years, including fifteen initial or revised applications, assessments, or agreements. Fragmented data systems, multiple data controllers, and a changing data governance environment created challenges to using routine data, requiring study design modification.

Twenty-five individuals (15 women) participated, aged 40-87 (mean=62) years, BMI 40-77 (mean=55) kg/m^2: 20 participants (80%) were housebound. Incomplete census data identified a further 261 eligible individuals.

Weights ranged from 98.4 to 211.8 kg (mean=150 kg), with 16 participants requiring bariatric scales. For six people unable to stand, wheelchair scales (*n*=1), bed weighing scales (*n*=2), routine weights from care home records (*n*=2) or weight data from hospital records (*n*=1) were used. The standard portable stadiometer was usable for only one participant: Others required alternative measures from which to estimate height, which gave diverse heights.

Twenty-two different cross-sector community health and social care services were used. Only five participants had contact with weight management services. Twenty-four (96%) participants used three or more services, with longest care episode lasting over 14 years. Total annual service costs incurred by participants varied from £2,053 to £82,792 base case estimate, mean £26,594 (lower estimate £2,053 to £80,064, mean £22,462; upper estimate £2,053 to £88,870, mean £30,726), with greatest costs being for social care.

Nine women and three men (*n*=12) participated in qualitative interviews, aged 40-76 (mean 60) years, BMI ranged from 45-74 (mean 59) kg/m^2, eight were housebound. Three overarching themes were identified. Firstly, the hidden struggles of living with a larger body impacted all participants, including functional limitations affecting mobility and personal care. These contributed to a sense of being stuck physically, socially, and biographically, partially due to poor treatment options. A second theme found explicit weight bias was commonly, but not wholly, denied. However, most participants related implicit weight bias by a system structurally unprepared to care for people with severe obesity. The majority of participants showed strong internalised weight bias, linked to shame and self-blame for their poor function and larger bodies. Thirdly, a day-to-day coping theme highlighted strategies regularly used by participants: resigned acceptance, avoidance and denial, exercising choice, and support from informal carers.

Conclusion

Accurate prevalence data for the population with BMI ≥40 kg/m^2 is under reported. International health surveys could improve data availability by publishing disaggregated data beyond BMI ≥30 kg/m^2. Current practice regarding anthropometric measures likely excludes people with severe obesity and functional limitations. Specialist scales and standardised methods for height estimation appropriate for people with severe obesity are needed. Lack of data impairs surveillance of population trends, understanding of causation, societal provision for individuals living with higher weights, and the effectiveness of future service planning.

Practitioners face a complex approvals process to use data they routinely collect for research or evaluation purposes. Data sources for poorly documented community health and social care services exist and are navigable at an individual level. Population-level usage of such records needs developed.

Adults with severe obesity, including those under 65 years, may need sustained care from multiple community care services, with potentially high annual costs. Economic evaluations of obesity and weight management need to include these wider care costs to ensure completeness.

Participants experienced unmet physical and psychological care needs associated with their larger bodies, leading to poor quality of care and life. Given rising prevalence, changes to care services are required. Specific recommendations include staff training about needs of people with severe obesity, ensuring the physical infrastructure of care services can safely accommodate people with severe obesity, and improving access to effective, person-centred weight management treatments, with strategies to tackle internalised weight bias.

Future research could explore how the duration and severity of obesity affects an individual’s functional limitations, subsequent need for care, and quality of life.

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Publications arising from this thesis

1. Williamson, K., Nimegeer, A. & Lean, M.E.J. (2020) *Rising prevalence of BMI ≥40 kg/m*^{2}*: A high-demand epidemic needing better documentation.* Obesity Reviews 21, 4, e12986
2. Williamson, K., Nimegeer, A. & Lean, M.E.J. (2022) *Navigating data governance approvals to use routine health and social care data to evidence the hidden population with severe obesity: A case study from a clinical academic's perspective.* Journal of Research in Nursing 27,1, 623-636
3. Williamson, K., Blane, D.N. & Lean, M.E.J.(2022) *Challenges in obtaining anthropometric measures for adults with severe obesity: A community-based study.* Scandinavian Journal of Public Health Epub ahead of print doi.org/10.1177/14034948221089111
4. Williamson, K., Blane, D.N., Grieve, E. & Lean, M.E.J.(2022) *Overlooked and under-evidenced: Community health and long-term care service needs, utilisation, and costs incurred by people with severe obesity.* Clinical Obesity e12570, https://doi.org/10.1111/cob.12570

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Conference presentations arising from this work

1. Williamson, K., Vlassapoulos, A., Nimegeer, A. & Lean, M.E.J. *Scaling up: A critique of recent methods for measuring severe obesity in English and Scottish Health Surveys. UK Congress on Obesity*. University of South Wales, United Kingdom. September 2017 (Poster presentation).

2. Williamson, K., Nimegeer, A. & Lean, M.E.J. *"Conspicuously Invisible": The evidence gap regarding severe obesity (BMI ≥40 kg/m^2). UK Congress on Obesity.* Newcastle, United Kingdom. September 2018 (Poster presentation).

3. Williamson, K., Nimegeer, A. & Lean, M.E.J. *BMI documentation in routine General Practice. European Congress on Obesity.* Glasgow, United Kingdom. April 2019 (Poster presentation).

4. Williamson, K., Nimegeer, A. & Lean, M.E.J. *Measuring height for people with high body mass index at home: Standing up for inclusion. European Congress on Obesity.* Online. May 2021 (ePoster presentation).

5. Williamson, K., Nimegeer, A. & Lean, M.E.J. *Challenges in weighing community-dwelling individuals with high body mass index: A barrier to accessing safe, routine care. European Congress on Obesity*. Online. May 2021 (Online oral presentation).

6. Williamson, K., Nimegeer, A. & Lean, M.E.J. *Navigating data governance approvals to use routine health and social care data to evidence an invisible population, a case study from a clinical academic perspective. Health Services Research UK conference*. Online. July 2021 (Video Oral presentation).

7. Williamson, K., Blane, D.N., Grieve, E. & Lean, M.E.J. *Community health and social care service utilisation by people with severe obesity: A micro-costing study. European Congress on Obesity.* Maastricht, Netherlands. May 2022 (ePoster presentation).

8. Williamson, K., Blane, D.N., Grieve, E. & Lean, M.E.J. *Shut-ins: Shut out of the evidence base. UK Congress on Obesity*. Lancaster, United Kingdom. September 2022 (Invited speaker, oral presentation).

List of Accompanying Material

Appendix 1: Search strategy for Chapter 2

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Appendix 3: Interview schedule to support Chapter 6

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To S and L, I dedicate this thesis to you – for all you taught me in caring for you. I am saddened you are no longer with us. But your legacy lives on in this work. This is my effort to right some of the wrongs you suffered and improve care. I hope that I have done you proud.

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The views expressed herein are my own and do not represent those of my employers or funders.

Author's Declaration

I confirm that the study presented in this thesis is my own work. The conception and design, data acquisition, organisation, analyses and interpretation, have been undertaken by me with input from my supervisors (Dr Amy Nimegeer 2016-2019; Dr David N Blane 2019-2023 and Prof Michael E J Lean).

This thesis is submitted in journal format, with Chapters 2 to 5 published and Chapter 6 written for submission for publication. These chapters are presented in manuscript form.

For each of these papers I was the primary author, wrote the first draft of each paper, submitted it, and revised the manuscript based on reviewers' feedback, with guidance from my supervisors. A statement at the start of relevant chapter outlines specific contributions. Chapters 1 and 7 are unpublished and written specifically for this thesis.

Kathryn Williamson

Definitions/Abbreviations

ADLs: Activities of Daily Living

AHP: Allied Health professional

BAPEN: British Association for Parenteral and Enteral Nutrition

BIV: Biologically Implausible Value

BMI: Body Mass Index

COPE: Committee on Publication Ethics

COREQ: Consolidated criteria for Reporting Qualitative Research

CPAP: Continuous Positive Airway Pressure

CPN: Community Psychiatric Nurse

CPRD: Clinical Practice Research Datalink

DN: District Nurse

DAPA: Diet, Anthropometry and Physical Activity

DHS: Demographic and Health Surveys

DPIA: Data Protection Impact Assessment

DSA: Data Sharing Agreement

EBP: Evidence Based Practice

EHIS: European Health Interview Survey

EHR: Electronic Health Record

ELMS: Equipment Loan Management System

GDPR: General Data Protection Regulation

GP: General Practitioner

h: hours

HIG: Health Improvement Grant

HRA: Health Research Authority

HSCP: Health and Social Care Partnership

IT: Information Technology

IWB: Internalised weight bias

Kg: Kilogram

LIST: Local Intelligence Support Team

LTC: Long-term care

MUST: Malnutrition Universal Screening Tool

NCD: Non-Communicable Disease

NCD-RisC: Non-Communicable Disease (NCD)-Risk Factor Collaboration

NMAHP: Nurse, Midwife and Allied Health Professional

NHS: National Health Service

OECD: Organisation for Economic Development

OOH: Out of Hours services

OT: Occupational Therapist

PoC: Package of Care

PBPP: Public Benefit and Privacy Panel

REC: Regional Ethics Committee

SAS: Scottish Ambulance Service

SES: Socioeconomic Status

SIMD: Scottish Index of Multiple Deprivation

SW: Social Worker

TDR: Total Diet Replacement

UK: United Kingdom

US: United States

USAID: United States Agency for International Development

WHO: World Health Organisation

WM: Weight Management

WOF: World Obesity Federation

Yrs: years

Chapter 1 Introduction

1.1 Overview

This chapter will introduce the study, defining key terms and outlining the context which led to the study's inception. It will include a brief summary of the relevant wider evidence base, highlighting identified gaps which the study sought to address. It concludes with study specific research questions and objectives.

Chapters 2 to 5 are made up of brief commentaries accompanying published papers. Chapter 6 is a qualitative paper written for submission to a journal. Chapter 7 is a Discussion chapter, drawing together overall themes and making recommendations for future practice and research.

Given that published papers include necessary introduction, methods and discussion, these elements have been minimised elsewhere to avoid repetition.

1.1.1 Terminology

Since starting this study in 2016, the terminology used to discuss excess body weight has received increasing attention, motivated by recognition of the stigmatising effect of language (Puhl, 2020). Much of this has focussed on destigmatising communication between health professionals and people receiving care, especially weight management treatment (Albury et al., 2020). However, the scope is broader, with wider stakeholders including journals (Fearon et al., 2022), health records (Gagliano-Juca and Apovian, 2021), and different paradigms, such as fat studies and critical sociology (Murray, 2007, Stoll and Egner, 2021). Currently, no single term appears universally acceptable (Howes et al., 2021), although "morbidly obese" is commonly discouraged (Gagliano-Juca and Apovian, 2021) and person-first language is widely encouraged (Albury et al., 2020). This thesis uses "severe obesity" (except for parts of Chapter 6) as the least stigmatising, but most widely adopted, term by clinicians, equating with the highest Body Mass Index (BMI) category of ≥40 kg/m^2, as per the United States (US) Centers for Disease Prevention and Control categorisation (Centers for Disease Control and Prevention, 2022).

BMI offers a simply calculated index of weight-for-height commonly applied at a population level to screen for different weight categories, strongly correlating with more direct measures of body fat and associated disease outcomes (Centers for Disease Control and Prevention, 2022). However, it is not a direct measure of body fat or body shape, having limitations at the individual level and should be part of a wider assessment when used at the individual level (Wharton et al., 2020).

1.2 Research motivation: Why the population with Body Mass Index (BMI) ≥40 kg/m^2?

> *"The important thing is not to stop questioning. Curiosity has its own reason for existing" Albert Einstein.*

1.2.1 Author's clinical perspective: Evidence based-practice?

This thesis is rooted in clinical practice. Since 1999, the author has worked as a district nurse caring for increasing numbers of individuals at home with severe obesity (BMI ≥40 kg/m^2), some in the 70-100 kg/m^2 region. As a caseload holder, the author was responsible for planning nursing care for these individuals, including tissue viability, continence, moving and handling, and anticipatory care. This entails liaising with general practitioners (GPs), and other members of the multidisciplinary team including social care, Scottish Ambulance Service (SAS), plus family members, regarding care provision, particularly if the individual's condition deteriorates requiring hospital admission. Additionally, staff safety is a key consideration especially in the relatively uncontrolled environment of people's homes. To execute these responsibilities well, practitioners are expected to use evidence-based practice (EBP), central to delivering the "Quadruple aim" in healthcare (Melnyk and Fineout-Overholt, 2022), defined as:

1. Improved patient outcomes,

2. Better patient experience,

3. Lower costs,

4. Improved experience for staff.

A problem arises when real-world experience suggests that there is little evidence to guide practice, meaning patients and clinicians experience the opposite of all four aims (Lumley et al., 2015, Agaronnik et al., 2021). This was the author’s experience in 2016, when starting doctoral studies.

1.3 Study context: Evidence base

To broadly highlight the rationale behind the study’s inception this section will briefly summarise the wider evidence base around severe obesity, with reference to Scotland where such evidence exists. The aim is to allow the reader to broadly understand the wider study context, and the relevance of the focus of this thesis, rather than providing full and detailed discussion of each issue, which is beyond the scope of this thesis. Further detail about different elements of the study can be found in the individual chapters (particularly the Introduction and Discussion sections).

1.3.1 Causes of obesity

In recent years, it has been increasingly accepted that obesity (BMI ≥ 30 kg/m^2) is a complex, chronic disease process characterised by excess body fat that impairs health (Bray et al., 2017, Wharton et al., 2020). It is no longer singularly seen as a lifestyle or behavioural choice, but a complex interaction of heterogeneous environmental, genetic, biologic and socioeconomic factors (Bray et al., 2017). Patterns of socioeconomic status (SES) and severe obesity vary globally but are associated with lower SES in the United Kingdom (UK) (Booth et al., 2017, Green and Rowe, 2020).

1.3.2 National prevalence data

In Scotland, the proportion of adults with BMI ≥ 40 kg/m^2 is increasing faster than other BMI groups. Prevalence of severe obesity in Scottish women (aged 16-64 years) has risen five-fold from 1% in 1995 to 5% in 2017, whilst prevalence for the men doubled from 1 to 2% (Scottish Government, 2018b). Rates for adults over 65 years were not reported in 1995, hence difficulty comparing prevalence for all adults. The latest statistics released post COVID-19 pandemic, notably using self-reported weight and height, show rates reaching 9% of women aged 45-54 years (Figure 1.2) (Scottish Government, 2022b). Most concerningly, rates for 16-24 year olds for both men and women are triple those in 1995 (Figures 1.1 to 1.3) (Scottish Government, 2022b).

Overall trends for adult prevalence of severe obesity appear similar in England (Figure 1.4), although with proportionately greater increases in men (from 0.3% in 1993-95 to 2.2% in 2017-19) compared to women (from 1.5% in 1993-95 to 4.5% in 2017-19) (Public Health England, 2021). Availability of international data will be addressed in detail in Chapter 2, alongside a critique of health survey methodology.

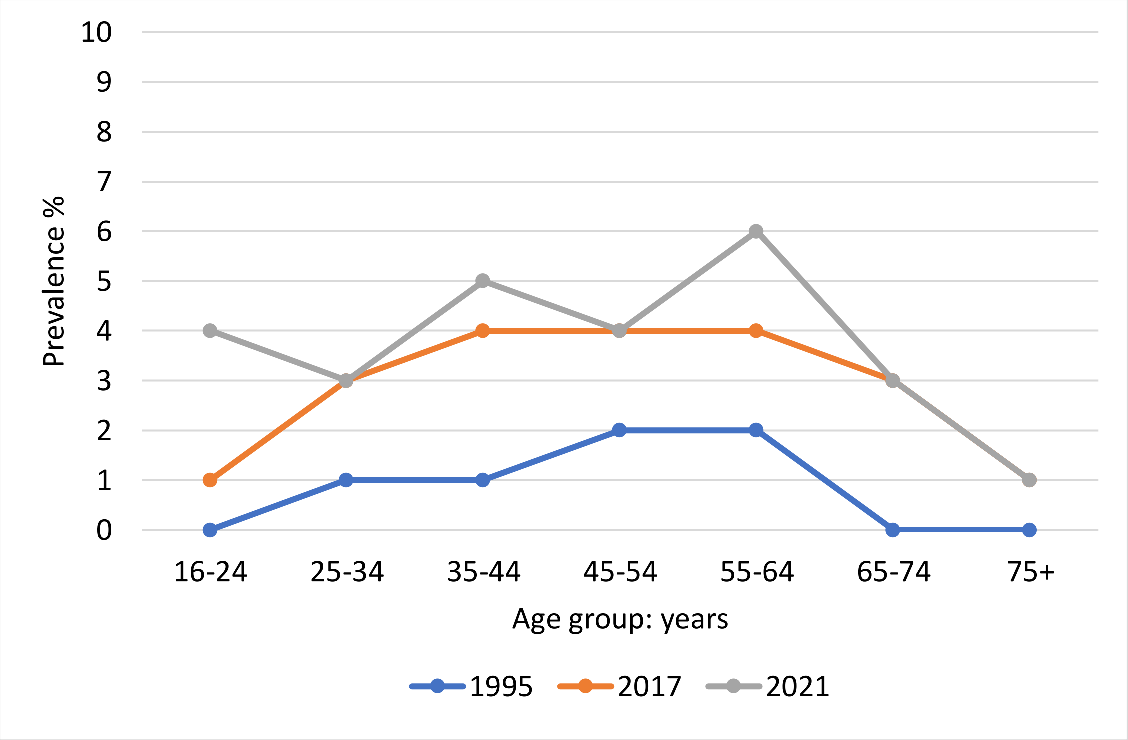


Figure 1.1 Scottish BMI ≥40 kg/m^2 prevalence trends by age group for all adults: 1995, 2017 and 2021

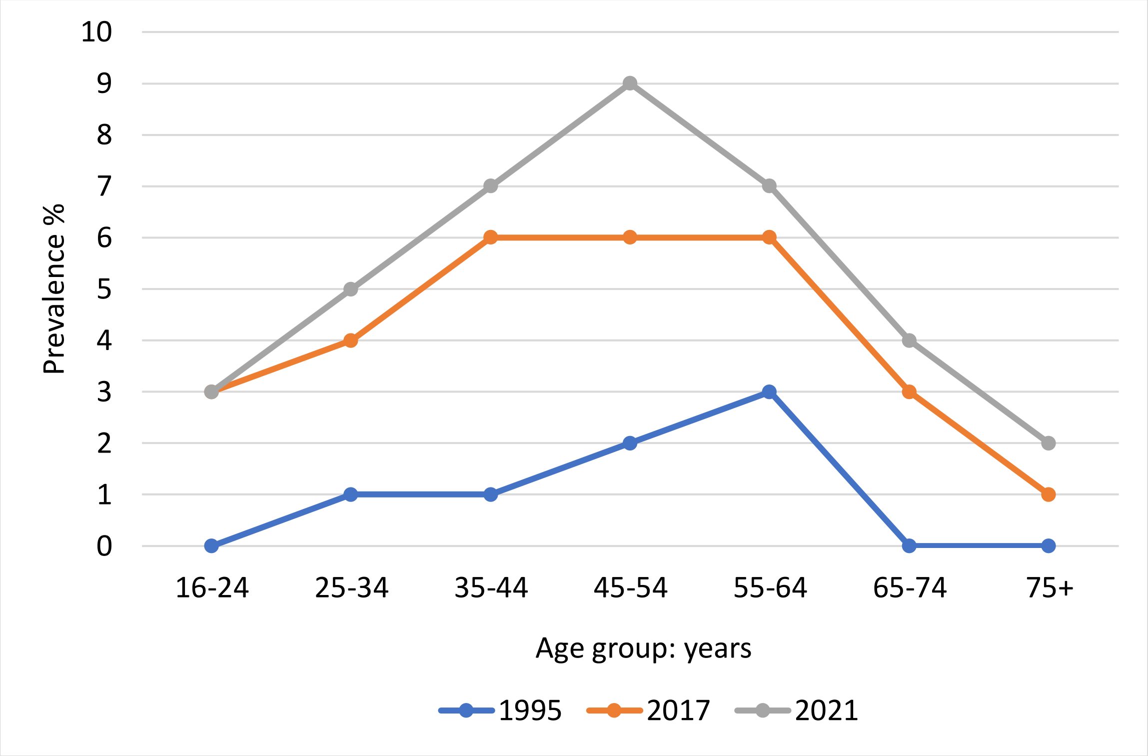


Figure 1.2 Scottish BMI ≥40 kg/m^2 prevalence trends by age group for women: 1995, 2017 and 2021

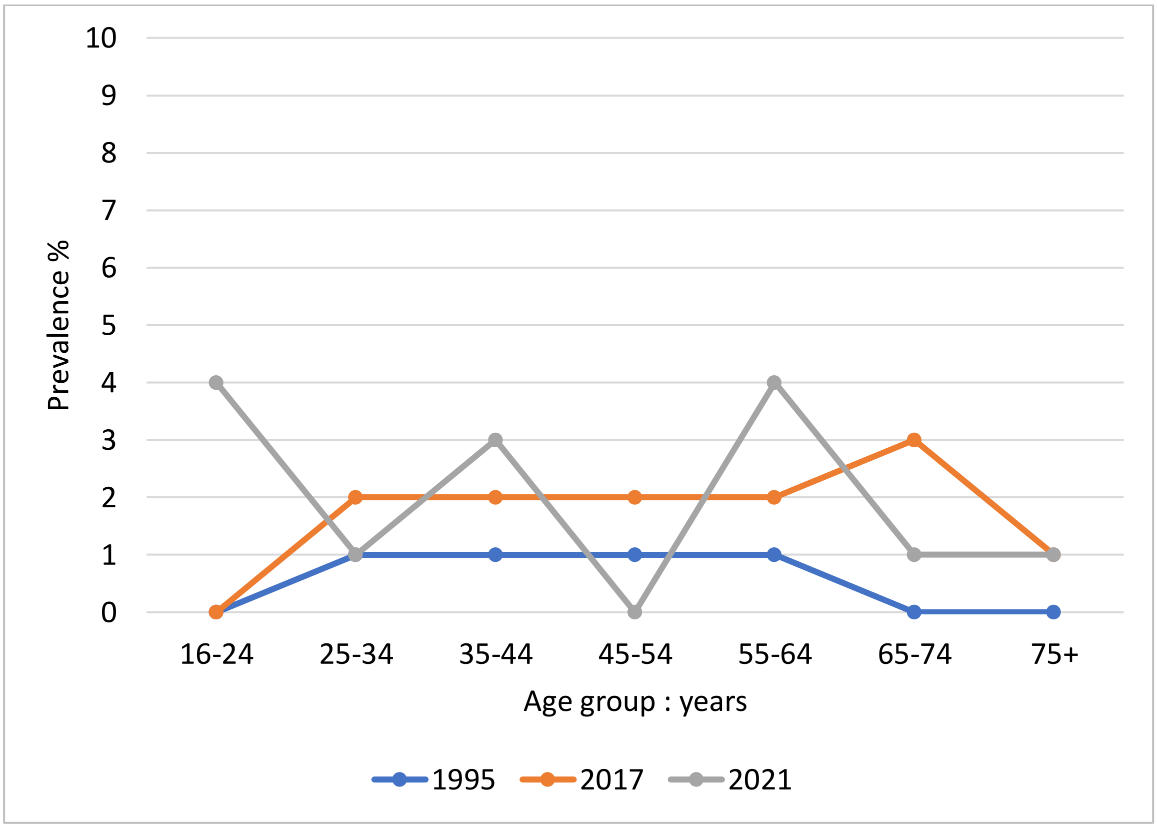


Figure 1.3 Scottish BMI ≥40 kg/m^2 prevalence trends by age group for men: 1995, 2017 and 2021

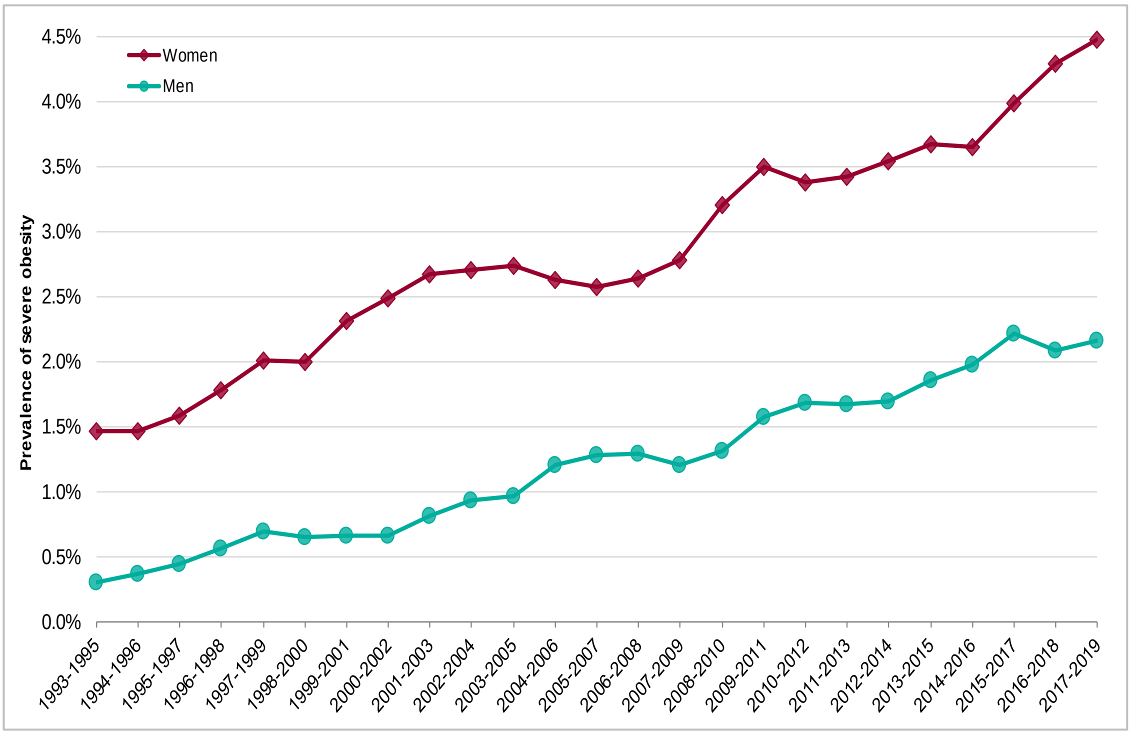


Figure 1.4 Trends in BMI ≥40 kg/m^2 severe obesity prevalence among adults Health Survey for England 1993 to 2019 (3-year average)

Legend: (reproduced from Public Health England, 2021, no permission required)

1.3.3 Medical consequences of severe obesity

Large-scale epidemiological studies have robustly documented the medical consequences of obesity as dose responsive, with higher BMI increasing risk of multimorbidity from type 2 diabetes, cardiovascular disease (hypertension, dyslipidaemia, stroke, myocardial infarction and coronary heart disease), obstructive sleep apnoea, osteoarthritis, gallstones, breast and endometrial cancer, asthma and depression (Booth et al., 2014, Haase et al., 2021, Global Burden of Disease 2015 Obesity Collaborators, 2017, Bray et al., 2017). People with BMI ≥30 kg/m^2 have more than a 12-fold risk of complex multimorbidity (four or more diseases) than those with healthy weight (BMI 18.5-24.9 kg/m^2) (Kivimäki et al., 2022). Additionally, people with BMI ≥35 kg/m^2 are estimated to lose 7-10 years of disease-free life associated with excess weight (Nyberg et al., 2018) and are at increased risk of premature death (Moussa et al., 2019b). Although recent improvements in management of cardiovascular comorbidities are improving active life expectancy (Zhang et al., 2019b).

1.3.4 Medical costs

A systematic review of international studies using individual participant data found direct medical costs for people with BMI ≥40 kg/m^2 are at least 50% greater than those of healthy weight (BMI 18.5–24.9 kg/m^2) (Kent et al., 2017). Although the failure to disaggregate costs within the BMI ≥40 kg/m^2 category, means that possible heterogeneity within this category is unknown (Grieve et al., 2013). In 2015 the annual cost of excess weight to NHS Scotland was estimated at £600 million (Castle, 2015). However, this costing is premised on an extrapolation to Scotland based on population share and uses English data from 2006/7 (McNamee et al., 2017).

1.3.5 Weight management evidence

In response to rising prevalence, a burgeoning evidence base exists regarding weight management treatments for people with severe obesity, although more work is still needed. Such evidence is essential in trying to prevent some of the consequences outlined above, but is largely an adjunct to this study rather than the focus. However, it is helpful to draw out some key tenets to broadly frame the study.

Many barriers exist in even accessing treatment. Firstly, weight measurement is not routine in UK primary care with approximately a third of patients being weighed annually (Nicholson et al., 2019). Obesity is also poorly reported in inpatient records, with only 6% of patients having it noted in admission or discharge documentation (Srivastava et al., 2018). Even where it is recognised, referral to weight management services is influenced by multiple interacting factors including practitioner characteristics, negative perceptions, weight stigma and ease of referral route (Blane et al., 2020). Given limited weight management services and barriers to referral (Holt and Hughes, 2020, Skea et al., 2019), most people with severe obesity are not receiving weight management services, with up to 59% of those with severe obesity having no record of weight management in the past seven years (Booth et al., 2015). For those that do access treatment, there is no one-size-fits-all acceptable intervention (Skea et al., 2019).

Bariatric surgery is recommended for people with BMI ≥40 kg/m^2 who have tried non-surgical measures and are assessed as suitable (National Institute for Health and Care Excellence, 2014). However, fewer than 1% of people eligible are receiving (publicly-funded) surgery in the UK, with rates declining (Gulliford et al., 2016). Average weight loss from a lifestyle weight management programme is around 3% (National Institute for Health and Care Excellence, 2014), which is unlikely to produce clinically important changes for people with severe obesity, with weight loss of >10% needed (Warkentin et al., 2014). Realistic expectations are key, as the likelihood of people with severe obesity achieving healthy weight status (BMI 18.5–24.9) is very low: 1 in 1290 for men and 1 in 677 for women (Gulliford et al., 2016).

The REBALANCE project, a systematic review of long-term randomised controlled trials of weight management for people with BMI ≥35 kg/m^2 found poor representation of those most at risk, including women, those with mental health comorbidity, and lower SES, making findings poorly generalisable to a UK context (Robertson et al., 2022). It concluded that for lifestyle weight management programmes social interaction was generally valued but the physical and mental comorbidities of severe obesity can reduce participation (Skea et al., 2019). Evaluation of approaches for people with BMI ≥40 kg/m^2, whose presentation can be more complex was specifically recommended (Avenell et al., 2018). Longer term follow-up is needed to more fully understand cost-effectiveness (Avenell et al., 2018).

The REBALANCE review was conducted before the Covid-19 pandemic, which precipitated greater use of digital health, such as internet, telephone, and app-based support. These approaches broaden potential for engagement, notably for those who may struggle to access in-person interventions (Hinchliffe et al., 2022). More recently, significant weight loss (≥15 kg) has been achievable for some individuals in primary care, using Total Diet Replacement (TDR) with appropriate support (McCombie et al., 2019). Currently, the development and application of new anti-obesity medications, such as semaglutide and tirzepatide, offer further potential for effective treatment of obesity (Ryan, 2021).

1.3.6 Gaps in the evidence base

In this section, gaps in the evidence base for people with severe obesity will be outlined. These will primarily come from the author's perspective of a community-based practitioner, looking for evidence to guide their practice.

1.3.6.1 Lack of evidence to guide care of people with severe obesity

Numerous case studies document specific care challenges experienced by professionals providing care for individuals with severe obesity including appropriate anticipatory care planning at end of life (Baumrucker et al., 2009), serious injury after relatively minor fall (Edwards et al., 2013), management of massive localised lymphoedema (Fife, 2014), abdominal lymphoedema (Fadel et al., 2017), pressure ulcers (Gallagher Camden et al., 2007), inability to use diagnostic scanning (Bhalla et al., 2021) and functional rehabilitation including mobilisation (Anaf et al., 2017, Tandiono and Jayaratne, 2017). Such case studies are published because they highlight novel, challenging cases, of interest to colleagues. Collectively, they highlight the emerging, often unmet, care needs of a growing population. They potentially mark the start of an evidence base, hopefully stimulating further research, but are limited in offering practitioners clinical guidance.

Since the inception of this study, the Canadian clinical practice guidance for obesity in adults has been published, aimed at primary health care professionals (Wharton et al., 2020). This contains a chapter on enabling participation in Activities of Daily Living (ADLs) for this population, which highlights some of the wider care needs of people with obesity (Forhan et al., 2020). However, paucity of evidence affects the most basic care needs, such as skin-hygiene (Cowdell and Radley, 2014), medication dosages (Polso et al., 2014, Barletta and Erstad, 2022), mental health support (Ellison et al., 2020), personal care assistance (Sefcik et al., 2022) and emergency evacuation procedures (Gray et al., 2022). The result is that staff employ custom and practice around these fundamental care processes rather than evidence-based care (Cowdell and Radley, 2014). A key example from the author's own practice would be cleansing and maintenance of skin in deep skin folds, which are liable to be frequently moist, at high risk of fungal infections, difficult to visualise, prone to pressure from the tissue above and can be extensive, requiring significant staff input. Yet available evidence consists of custom and practice based on contradictory clinical opinion, (Cowdell and Radley, 2014). Consequently, people with severe obesity have high potential for receiving poor quality care (Barletta and Erstad, 2022).

Therefore, it is perhaps unsurprising, that many health professionals find caring for people with severe obesity difficult. This relates to being unsure of appropriate terminology around body size (Toft and Uhrenfeldt, 2015, Christenson et al., 2018, Hales et al., 2019b), expecting negative outcomes (Dewhurst et al., 2017), lacking training (Lumley et al., 2015, Woods et al., 2016, Lunt et al., 2022), fear of stigmatising individuals (Christenson et al., 2018, Hales, 2018), being unsure of suitable services (Henderson, 2015, Malterud and Ulriksen, 2010), lack of interdisciplinary approaches (Asselin et al., 2016), and not having the right equipment (Drake et al., 2010, Rose et al., 2010, Woods et al., 2016, Lumley et al., 2015, Rinne et al., 2018). Many of these reports come from nurses, midwives, and allied health professionals (including physiotherapists, occupational therapists (OTs), podiatrists), commonly termed NMAHPs, distinguishing their roles from medical doctors. The issues raised particularly affect community-based practitioners, who often lone-work, largely “behind closed doors”, making them feel professionally isolated when managing complex care (Swift and Punshon, 2019).

Recent improvements in mortality are not matched by reduced disability in people with obesity, with reported level of functional impairment increasing over time (Alley and Chang, 2007) and increasing BMI (Kyrou et al., 2011). There are, however, fewer studies evidencing the impact of obesity on physical disability and functional limitations (Wong et al., 2015, Backholer et al., 2012, Forhan and Gill, 2013). The functional limitations associated with severe obesity result in people more likely to need help managing ADLs, such as washing and dressing, skin care, mobilising, and toileting (Backholer et al., 2012, Pain and Wiles, 2006, Felix et al., 2009, Howard et al., 2016). This poses previously unknown challenges for care providers (Beitz, 2014), particularly nurses, allied health professionals and social care staff tasked with enabling or performing ADLs for people (Drake et al., 2008, Schuldt et al., 2021, Ellison et al., 2020).

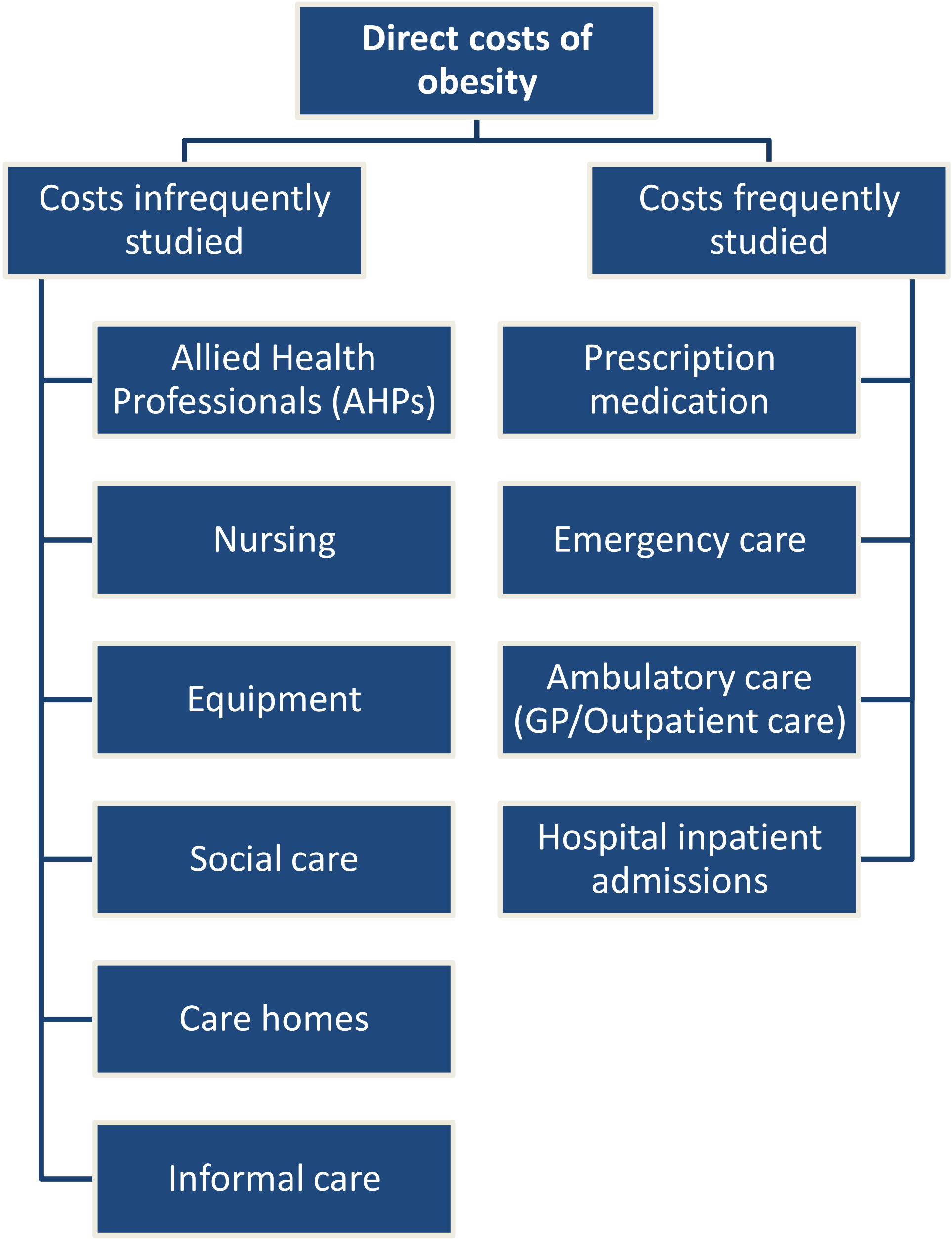


Figure 1.5 Types of costs frequently and infrequently included in cost of obesity research

1.3.6.2 Community health services: Utilisation and costs

Certain utilisation patterns and costs related to obesity are relatively frequently studied: prescriptions, hospital inpatient and outpatient and physician/general practitioner episodes (Kent et al., 2017). Whilst significant, these do not fully represent the range of professionals and services involved in care of individuals with severe obesity, particularly in the community, where most people live, as summarised in Figure 1.5.

One explanation for the lack of evidence is the paucity of data easily available. Primary care medical practitioners have articulated a sense of persistent challenge regarding relevant research, with much focussed on secondary care (van Weel et al., 2012), but do at least have a voice through academic primary care. McHugh et al (2015) note the lack of Irish data available on allied health services, including social care, dietetic services, and community-based services such as public health nurses.

The same is true in the UK for district nurses, with poor data availability on activity, with no equivalent of Hospital Episode Statistics (The King’s Fund, 2016), meaning lack of research is cited as a specific barrier to implementing evidence-based practice in district nursing (Mathieson et al., 2018). This makes the housebound population they care for, who by definition are at high risk of social isolation and functional limitations, problematic for both service providers and researchers to access. In contrast to the relatively well-documented population using weight management services (Farrell et al., 2021), the housebound population could be termed a “seldom-heard” population (Ní Shé et al., 2019).

1.3.6.3 Social care: Utilisation and costs

There are a lack of national and local level data on the impact of obesity on social care in the UK, but anecdotal reports suggest that for a small group of individuals, social care costs are likely to be significant (Local Government Association, 2020). The only national studies on obesity and social care are limited to people in England >65 years old, as they use data from the English Longitudinal Study of Aging (Copley et al., 2017, Gousia et al., 2019, Nizalova et al., 2020). Copley et al’s study excludes those in care homes, who by definition are likely to have greater health and social care needs, meaning that costs calculated are potentially conservative. Despite this, the results clearly demonstrate a J-shaped relationship between increasing BMI and need for social care, with care for those with BMI 40 kg/m^2 costing double that of BMI 23 kg/m^2 (£1,086 vs £599), although as an observational study, causation cannot be assumed. Gousia et al found that those with BMI ≥40 kg/m^2 were 2.12 times, and those with BMI ≥45 kg/m^2, were 5.8 times more likely to use formal care than those with BMI 18.5-24.9 kg/m^2 (Gousia et al., 2019).

Walker's 2003 study found over 95% of treatment costs for obesity are spent on the consequences of excess weight, which could include social care, not treating the obesity itself (Walker, 2003). However, this was during a time of rapidly rising severe obesity prevalence rates and before social care was expanded to its current scale, so needs updated. A rapid review for Obesity Action Scotland in 2019 found a

> *"startling lack of information or data regarding the impact of obesity on social care" (Obesity Action Scotland, 2019, p12).*

Indeed, it notes that whilst health and social care are often mentioned, social care is seldom considered separately (Obesity Action Scotland, 2019). Thus, the current cost of obesity to the wider care system, including social care, is currently unknown.

1.3.7 Equipment & adaptations

Despite being highlighted as an issue in the early 2000s (Lapane and Resnik, 2006, Pain and Wiles, 2006), care equipment (for example, beds, chairs, shower chairs) for people with severe obesity is still most frequently highlighted with regard to its absence or inadequacy (Parkinson and Thompson, 2021, Dockrell and Hurley, 2020, Lunt et al., 2022). There are few specific examples of use and costs associated with specialist equipment and adaptations in the evidence base, despite the essential nature of such equipment (Wiggerman et al., 2017, Dockrell and Hurley, 2020). Problems also exist using standard medical imaging equipment (Woods et al., 2016). This is despite access to specialist equipment being specifically advocated in current NICE (National Institute for Health and Care Excellence) (2014) guidance.

1.3.7.1 Research validity for practice context

Concerningly, many studies that could help to evidence the population apply an upper weight or BMI cut off, excluding people above a certain threshold as outliers or having biologically implausible values (BIV) according to WHO guidance (Freedman et al., 2015). In young people's and children's datasets, readings deemed as "BIVs" based on previous assumptions have been shown to very likely be correct, demonstrating population progression into higher weights than previously thought possible (Freedman et al., 2016). Without data demonstrating the accuracy of these high values as a new normal, researchers will fail to be inclusive of the whole population. A highly cited 2005 study on costs of severe obesity capped the weight limit at 158 kg (25 stone) (Arterburn et al., 2005). Given the increase and spread of the current BMI ≥40 kg/m^2 population, using the same cut off today would exclude a significant proportion of the desired cohort, thereby skewing the results. Documenting the fullest possible range of BMIs is necessary to comprehensively understand the extremes of population BMI, particularly at the right hand “tail” of the population distribution curve, which now includes many more people than it did 30 years ago (Public Health England, 2021).

1.4 Study context: Epistemic injustice: the need for different knowledge

As outlined above, the context framing this study is that of a care professional, whose work is largely absent from the evidence base, caring for a marginalised population also largely absent from evidence-based practice. In determining the study’s aims, the author was committed to “giving voice” to an alternative perspective, that of those living with severe obesity who are largely not accessing weight management treatment, instead accessing care associated with the disability and consequences of severe obesity. For the author, this was people with BMI as high as 100 kg/m^2 living, and dying, in unsuitable homes. The term “conspicuously invisible” has been used to describe their physical visibility due to body size, but invisibility in other ways such as strategic planning (Gray and MacDonald, 2016), appearing existentially unknown, by those with power to support and develop practice, such as senior managers, policy makers and researchers.

Capturing the voices of marginalised groups is important, so that their needs are not overlooked by service planners (Gray et al., 2022). Presently, the evidence base overwhelmingly focusses on the views of those who seek treatment by participating in weight management programmes, with a paucity of evidence about potential participants who do not seek treatment, or those who drop out of treatment (Avenell et al., 2018).

Subsequent exploration has led to the realisation that this active response resonates with the theoretical and philosophical approach of epistemic injustice, the crux of which concerns a person being wronged “specifically in her capacity as a knower” (Fricker, 2007).

Byskov identifies five different conditions that can be used on a sliding scale, to determine if someone is wrongly discriminated against, resulting in an epistemic injustice, and to what degree (Byskov, 2021). Table 1.1 summarises these and how they relate both to people with BMI ≥40 kg/m^2 and to district nursing as a professional group.

The author’s clinical experience prior to commencing doctoral studies, was of under representation of people with severe obesity who are not using weight management services but who need support to live in the community, due to disability either caused by, or exacerbated by, severe obesity. Neither their voice, nor the voice of people caring for them, were represented in the literature about severe obesity, or in policies dedicated to dealing with obesity, or at conferences about obesity.

Providing managers with knowledge about the need for service development, using first hand case studies, real-life risk assessments and even taking managers to visit patients themselves, was met with the request for further, often quantitative, knowledge. Academics and policy makers, focussed on weight management, appeared to find the very concept of people with severe obesity not in weight management, hard to comprehend. Thus, the knowledge of the problem from a district nurse’s perspective, struggling to find large enough dressings to cover wounds related to severe obesity, contrasted markedly with the knowledge of the problem from people with power to influence change.

Ironically, the opportunity for change presented itself in a chance conversation with a well-established medical academic, whose clinical experience supported the author’s view, and who agreed to act as doctoral supervisor.

Table 1.1 Byskov's five different conditions relating to epistemic injustice

Condition: key principles	Aspect of (in)justice	How population with BMI ≥40 kg/m^2 meets the condition	How district nursing meets the condition
Disadvantage: epistemic or socioeconomic	Unfair outcome	Poorly represented in evidence; link with lower socioeconomic status	Poor evidence base and representation in research
Prejudice	Unfair judgement about the capacity of/for knowledge	Obesity as stigmatised condition	Historically female occupation; focussed on "dirty work" of bodies[1]
Stakeholder	Unfair denial of rights	Largely excluded from effective treatment	Largely excluded from decision making about services/evidence base
Epistemic	Unfair denial of knowledge	Lived experience of severe obesity	Lived experience of care provision/unmet need largely ignored
Social Justice	Unfair existing vulnerability	Difficulties accessing treatment	Physically & professionally isolated, making it difficult to engage at an organisational level

[1] (Twigg, 2000)

1.5 Local scoping work

Initially two scoping exercises were undertaken to explore the evidence base and inform study design. The first of these assessed locally available sources of health data, routinely used by the author in care delivery, discussed below.

The second was a scoping review on availability of BMI ≥40 kg/m^2 data internationally, subsequently published (Williamson et al., 2020) and presented in Chapter 2.

1.5.1 Local scoping data

In 2014, the author was one of several clinicians in the Lothian Health board area of Scotland, UK (an area that includes the capital city of Edinburgh and its surrounding area) who created a Bariatric Forum, aiming to create a business case for service development to managers. In 2015-16, informal approaches were made through the Bariatric Forum to a range of NHS Lothian clinical services, largely in primary care, in a pragmatic approach to explore service utilisation data. Whilst this was not a systematic approach, its purpose was to scope out breadth of data available and explore how a more systematic approach could be adopted for a study. Information came directly from practitioners (NHS and local authority), in relation to their own practice caring for individuals with BMI ≥40 kg/m^2. Sources of data included medical and non-medical, health and local authority, support services and those involved in discharge planning.

1.5.1.1 General Practitioner (GP) Data

A convenience sample of two GP practices, geographically located in areas at different ends of the Scottish Index of Multiple Deprivation (SIMD), both with list sizes around 8,000, provided headline aggregate data easily available from Electronic Health Records (EHRs). This evidenced the lack of BMI data, as low as 20% of the practice lists having any BMI recorded. Nationally the Clinical Practice Research Datalink (CPRD) database of primary care electronic records has 55% of its cohort without BMI records, confirming that poor BMI data recording is widespread (Booth et al., 2015). This creates a significant validity problem with analysing GP data. The reasons for this gap are likely to be multiple, with potential contributors including poor knowledge about effective treatments (Blane et al., 2015), recording of body weight being largely opportunistic, dependent on individuals attending the practice (Booth et al., 2015) and for those with BMI ≥40 kg/m^2 potentially lacking access to high-weight scales (Agaronnik et al., 2021).

1.5.1.2 NHS board records

Local health board EHRs include both inpatient and outpatient activity, together with some community health services. This records system does not comprehensively interface with general practice EHRs, which operate independently. In October 2017, local health board analytical staff found only 8.5% of adults ≥16 years (*n*=779,130) with a local postcode had at least one BMI measurement ever recorded in the relevant BMI field. Of these, 0.8% (*n*=6,434) had a BMI ≥40 kg/m^2 (Figure 1.6). Thus, it appeared that baseline recording of height, weight and BMI was currently poor, highlighting the need for improved data gathering to inform service design. Evidence from the US notes the under-documentation of obesity in inpatient admission or discharge plans with only 6% of patients having obesity documented (Srivastava et al., 2018).

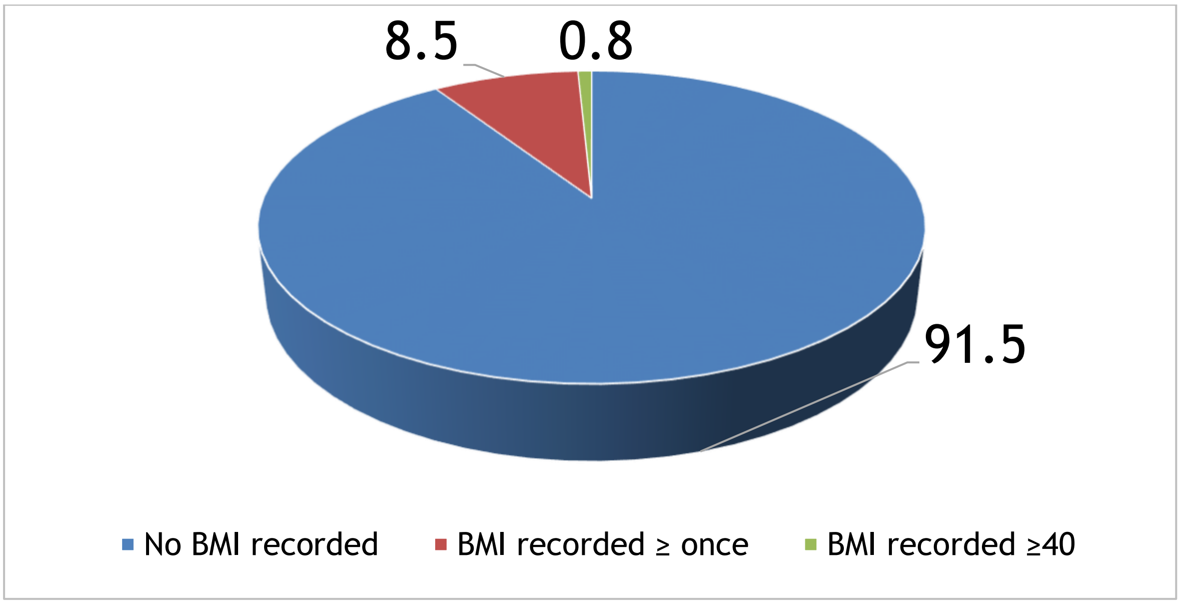


Figure 1.6 Percentage (%) of records with BMI data recorded in Trakcare NHS Lothian

Legend: BMI (kg/m^2)

1.5.1.3 Service utilisation costs

Hospital and care home estates are increasingly being adapted to cater for individuals with severe obesity. Independently, all district general hospitals within the local health board had combined two standard bed spaces to create a bariatric bed space, altering bathing and toileting facilities and adding a gantry hoist to assist manual handling. Whilst no costs were available, retrofitting facilities to make them accessible for people with severe obesity is known to be expensive (Dutta et al., 2018). One local authority care home had building adaptations to facilitate space for an individual with severe obesity, with equipment alone costing over £12,000. A recently built local authority care home included two dedicated bariatric rooms, with local authorities elsewhere also responding to service need by building dedicated housing for people with severe obesity (Aberdeen City Council, 2018).

In addition to building modifications, essential specialist equipment can be required for care of people with severe obesity. This equipment often costs more than standard equipment, due to accommodating higher working loads and larger body habitus. Examples include bariatric beds costing £2,150 compared with standard hospital beds at £399 and a requirement for electric wheelchairs at >£2,500, due to safety issues using standard basic attendant-propelled chairs at £400. Table 1.2 gives examples of indicative costs for specialist adaptations and equipment, provided by Bariatric Forum colleagues.

Table 1.2 Indicative costs for housing modifications

Adaptation	Cost (£)
Floor strengthening/door widening property[1]	20,000
Wessex through-floor lift[2]	13,000
Tracking hoist	6,300
Door widening/bespoke door adaptation	3,000
Structural engineer initial survey	1,000

Legend: [1]provided by OT colleagues, based on recent clinical cases; [2]stair lift not suitable due to weight limit

1.6 Study aims

The aim is to highlight the population with BMI ≥40 kg/m^2 using community health and social care services as an orphan area of research, of which many outside front-line care provision, even within weight management, may be unfamiliar. There is an urgent need for research to better characterise this population (Green et al, 2016) to better inform clinicians, researchers and policy makers alike. Thus, study outcomes hope to support both the "Quadruple aim" and future research looking at development of specific services for people with BMI ≥40 kg/m^2.

A key aim in doing a basic health economic analysis is to illustrate the largely undocumented costs to current service budgets of caring for this potentially high resource usage population. This is needed to inform both service planning and comprehensive economic evaluations of weight management strategies whilst stimulating further research into optimal care pathways and management of the population group. Also, there is potential for disaggregating costs by BMI group, although the small numbers of participants make this tentative and exploratory.

1.7 Research Questions

1.7.1 Primary Objective

The primary objective was to better characterise the population with BMI ≥40 kg/m^2, in a defined community-dwelling population, who require help at home.

Research questions associated with this were:

1. How many people known to health and social care services have a current BMI ≥40 kg/m^2?

2. How many of these are known to be housebound or in care?

3. What health and social care services does the BMI ≥40 kg/m^2 population use?

4. What are the costs of these health and social care services?

5. What are participants’ experiences of using these services?

1.7.2 Secondary Objective

Secondary objectives were to stratify findings for the BMI ≥40 kg/m^2 population into smaller BMI groups: 40-49/50-59/60-69/70-79/80-89/90-99/100+ kg/m^2. To describe the population by age, sex, SES & housebound status.

Research questions associated with this were:

6. What reasons contribute to them not having a BMI recorded (less mobile, need larger scales?)

7. What services are providing care?

    a. Purpose?

    b. Frequency?

    c. Duration?

    d. Episode length?

    e. How many participants are receiving, or have received, weight management?

    f. What are the costs of wider health and social care services (Occupational therapy, district nursing, social care, specialist equipment)? Do they vary by BMI group/age/sex?

Chapter 2 Scoping Review Rising prevalence of BMI ≥40 kg/m^2: A high demand epidemic needing better documentation

This chapter is published in Obesity Reviews (Open Access).

Williamson, K., Nimegeer, A., & Lean, M. (2020) Rising prevalence of BMI ≥40 kg/m^2: A high-demand epidemic needing better documentation. Obesity Reviews. 21, 4, e12986

Contributions: I conducted the search, with input from Paul Cannon (College librarian for Medical, Veterinary, and Life Sciences), and appraisal of sources, data extraction and data synthesis. I wrote the initial draft manuscript, with edits from my supervisors (MEJL and AN). I took the lead in manuscript submission and responding to reviewer comments, with input from my supervisors.

Thanks to Welcome Wami and Andy Peters for providing statistical advice.

2.1 Overview

We performed a scoping review looking at availability and quality of international BMI ≥40 kg/m^2 prevalence data to help explore the answer to research question 1:

- How many people known to health and social care services have a current BMI ≥40 kg/m^2?

This concluded that reporting of BMI ≥40 kg/m^2 prevalence data were poor globally, hampering both development of practice and research into this population group. The reporting of many national health surveys largely focussed on BMI categories 25-29 kg/m^2 and ≥30 kg/m^2, representing a missed opportunity. Data collection methods excluding those with mobility disabilities or those in institutions, such as care homes, also potentially affected the BMI ≥40 kg/m^2 population more than other BMI classes, potentially leading to under reporting.

Since publication of the scoping review in early 2020, the Covid-19 pandemic meant in-person data collection was suspended for national health surveys (NHS Digital, 2022), using self-reported data instead, affecting data production and quality. Whilst release of annual outcomes has now resumed, data at either extreme of the BMI range are potentially more unreliable, thus are either not being reported (NHS Digital, 2022), or, for Scotland, have some unusual outcomes. For example, 6% of men in Scotland aged 45-54 years were BMI ≥40 kg/m^2 in 2019 (Scottish Government, 2020a), but 0% in 2021(Scottish Government, 2022b). Fortunately, in-person data collection is planned to return, delivering more reliable data again, but further reporting cycles are needed to confirm patterns.

Data reporting, even by interested stakeholders, still needs further development. The Global Obesity Observatory, run by the World Obesity Federation has hugely developed both its quality and quantity of outputs in recent years, but does not yet disaggregate the BMI ≥30 kg/m^2 group into higher BMI classes (World Obesity Federation, 2022). This means patterns in the prevalence of BMI ≥40 kg/m^2 remain hard to discern globally.

Locally, the Scottish Health Survey has reported now using higher weight scales (200 kg maximum) as standard, with scales of 130 kg maximum weight now phased out (Scotcen (S. Christie), personal communication, 15th April 2021). Nevertheless, data collection organisations will need to further consider how they can be inclusive of people with severe obesity, whilst standardising and enabling data collection.

2.2 Abstract

Whilst previously rare, some surveys indicate substantial increases in the population with Body Mass Index (BMI) ≥40 kg/m^2 since the 1980s. Clinicians report emerging care challenges for this population, often with high resource demands. Accurate prevalence data, gathered using reliable methods, are needed to inform health care practice, planning and research.

We searched digitally for English language sources with measured prevalence data on adult BMI ≥40 kg/m^2 collected since 2010. The search strategy included sources identified from recent work by NCD-RisC (2017), grey sources, a literature search to find current sources and digital snowball searching.

Eighteen countries, across five continents, reported BMI ≥40 kg/m^2 prevalence data in surveys since 2010: 12% of eligible national surveys examined. Prevalence of BMI ≥40 kg/m^2 ranged from 1.3% (Spain) to 7.7% (USA) for all adults, 0.7% (Serbia) to 5.6% (USA) for men and 1.8% (Poland) to 9.7% (USA) for women. Limited trend data covering recent decades support significant growth of BMI ≥40 kg/m^2. Methodological limitations include small samples and data collection methods likely to exclude people with very high BMIs.

BMI ≥40 kg/m^2 data are not reported routinely in international surveys. Lack of data impairs surveillance of population trends, understanding of causation, and societal provision for individuals living with higher weights.

2.3 Introduction

Prior to the 1970s, Body Mass Index (BMI) ≥40 kg/m^2 was rare (Finkelstein et al., 2012). It was regarded as a pathological condition, deemed to indicate genetic, endocrine or other vulnerability, affecting a tiny, fixed population, with numbers too small for confident analysis (Sturm, 2007). Whilst prevalence can be minimal in low- to middle-income countries, contemporary studies suggest rising prevalence, with a current estimated global prevalence of 0.64% in men and 1.6% in women (NCD Risk Factor Collaboration, 2016). It is predicted that by 2025, the global numbers of underweight women will be surpassed by those with BMI ≥35 kg/m^2 (NCD Risk Factor Collaboration, 2016).

Although numbers may appear relatively small, compared with BMI ≥30 kg/m^2, frontline health professionals report increasing challenges in providing safe and effective overall healthcare for people with very high BMIs (Lumley et al., 2015). Emerging issues relate to providing for basic care needs such as appropriate positioning and handling (Gardner, 2013, Wiggerman et al., 2017), continence and skin-care (Rose et al., 2009), but also cover medical problems such as appropriate dosage of medicines (Polso et al., 2014), difficulty in performing medical imaging (Wiles et al., 2017) and complex psychological issues, including stigma, which impact treatment adherence (Thille, 2019). Evidence from several countries indicates that professional guidance or training about severe obesity for care-givers is minimal (Royal College of Physicians, 2013, Rinne et al., 2018, Poitou et al., 2018, Hales et al., 2016, Pokorny et al., 2009), threatening quality of care for this population, largely due to lack of awareness and limited evidence base (Zhang et al., 2013). This problem is compounded by stigmatisation over size and weight by the media, within society and among health professionals (Teachman and Brownell, 2001).

Furthermore, conventional behavioural weight management interventions have limited impact for BMI ≥40 kg/m^2 (Fildes et al., 2015). Only a minority of individuals access bariatric surgery (Gulliford et al., 2017), and effective non-surgical interventions are not yet widely available (McCombie et al., 2019). Thus, once individuals reach a very high BMI, the potential for sustained weight loss to improve quality of life and reduce secondary medical complications is limited. The severity and impact of muscular-skeletal complications reduce physical activity and mobility, increasing dependence on others and putting weight loss further out of reach. Consequently, individuals with BMI ≥40 kg/m^2 face reduced life expectancy (Global BMI Mortality Collaboration, 2016), multi-morbidity (Kivimaki et al., 2017), disability (Global Burden of Disease 2015 Obesity Collaborators, 2017), and reduced quality of life (Gupta et al., 2015). In turn, this disease burden produces multifaceted demands on health and social care services, raising direct and indirect costs (Grieve et al., 2013). Until recently, evidence on direct costs of BMI ≥40 kg/m^2 have been limited (Grieve et al., 2013). Total healthcare costs in the United Kingdom (UK) rise linearly, and double, as BMI increases from 20 to 40 kg/m^2 (Tigbe et al., 2013). A recent systematic review of international healthcare costs and BMI found costs for people with BMI ≥40 kg/m^2 to be 50% greater than for people with BMI 18.5–24.9 kg/m^2 (Kent et al., 2017). Costing studies typically exclude under-researched wider care costs, such as social care (Copley et al., 2017) and nursing home usage related to functional disability and often long-term provision (Zhang et al., 2019a, Copley et al., 2017), so current estimates are likely to underestimate the full costs. Forecasts indicate that increased resource usage will continue, including costs required to structurally adapt care facilities to the needs of people with BMI ≥40 kg/m^2, alongside providing suitable equipment and training for staff, that is currently missing (Cecchini, 2018).

The present scoping review explores the extent of international prevalence data on BMI ≥40 kg/m^2. It focusses on measured data, given the potential for error and bias with self-reported anthropometry by individuals who are overweight (Luo et al., 2019, Stommel and Schoenborn, 2009). We assessed the extent and quality of epidemiological reporting for the BMI ≥40 kg/m^2 category internationally, with a view to improving the documentation of this emerging high-demand population in future national surveys, to enable development of a reliable evidence base to guide effective care.

2.4 Methods

The primary epidemiological reports being investigated are health surveys, undertaken by governments for population surveillance to inform strategic policy priorities. Health surveys are not usually reported in the academic literature, unless for a secondary analysis focussed on a specific issue or sub-population, often with considerable time lag. Thus, database search terms for the primary survey would need to be very broad, making identification through academic databases highly resource intensive, with results prone to being incomplete and outdated. For the present scoping review, an alternative search strategy was therefore applied, based on the sources identified by the most recent systematic review of international BMI survey data, with additional searches to update and supplement these sources, outlined below.

Four key approaches were used to identify potential data sources:

1. Building on previous work

The NCD Risk Factor Collaboration (NCD-RisC) 2017 study on global BMI trends was chosen as a basis for the initial search, on the basis of its size and rigour: It used 2,416 sources of measured data, collected up to 2016 (NCD Risk Factor Collaboration, 2017). These sources were compiled from a systematic medical database search, supplemented by a worldwide network of researchers identifying and accessing national measurement surveys via interested parties, including World Health Organisation (WHO). Full details are given in the published paper and its appendix (NCD Risk Factor Collaboration, 2017). All 2,416 sources were screened as per the inclusion criteria in Table 2.1, with digital snowball searching used to locate individual data sources.

2. Digital searching of current grey literature sites

Searching of key international organisations websites known to compile BMI population survey data were undertaken, focussing on the Organisation for Economic Cooperation Development (OECD), the WHO and the World Obesity Federation (WOF).

3. Systematic database search

To ensure identification of any new sources since 2016 in the academic literature, a modified version of the NCD-RisC literature search was undertaken in Medline & Embase using the search terms in Appendix 1. Results from conference proceedings were deliberately included, as they can provide the first exposure of research analysis, highlighting new or updated data sources, whilst full articles commonly take much longer to publication, if indeed they are ever published in full. Sources were searched both for BMI ≥40 kg/m^2 data, but also to identify any new sources/health surveys not already located through parts 1 and 2 of the search process.

4. Digital snowball searching

Whilst NCD-RisC identified sources, individual sources needed located and accessed, often directly from a website of government agencies or international bodies. This was undertaken digitally, seeking previously unknown sources or articles.

All sources were screened using inclusion criteria in Table 2.1. Figures 2.1 & 2.2 represent the search process, with numbers of studies included and excluded at each stage. Searches took place between June and September 2019. Where successive or annualised surveys were identified, sources were checked for the most current data, with the most recent data retained. If multiple studies for the same country or source were identified, the one with the largest sample, or that provided the most information, to data extraction was retained. These pragmatic methods adopt a systematic approach to exploring the broad evidence landscape in an emerging area, highlighting gaps for future, more detailed research (Peters et al., 2017).

Table 2.1 Source inclusion and exclusion criteria

Included	Excluded
Reports BMI ≥40 kg/m^2 prevalence	Does not report BMI ≥40 kg/m^2 prevalence
Measured anthropometric data	Self-reported anthropometric data
Nationally representative data: Sampling strategy showing national coverage based on electoral roll/ census or similar, with at least stratification for age and sex.	Nonnationally representative, subpopulations by age/sex/rural/urban/ regional/community
Adults aged ≥15 years or older	Children & adolescents
Data collected in or since 2010	Data collected pre-2010
Data already compiled in a publicly available report/website[1]	Data requiring registration/searching through raw data[2]
Report in English language	Report not in English language
Not already identified by search	Already identified through alternative source

Legend:[1]for immediate use by decision makers, [2]may be available to academics, but requiring analysis & presentation prior to use by decision makers.

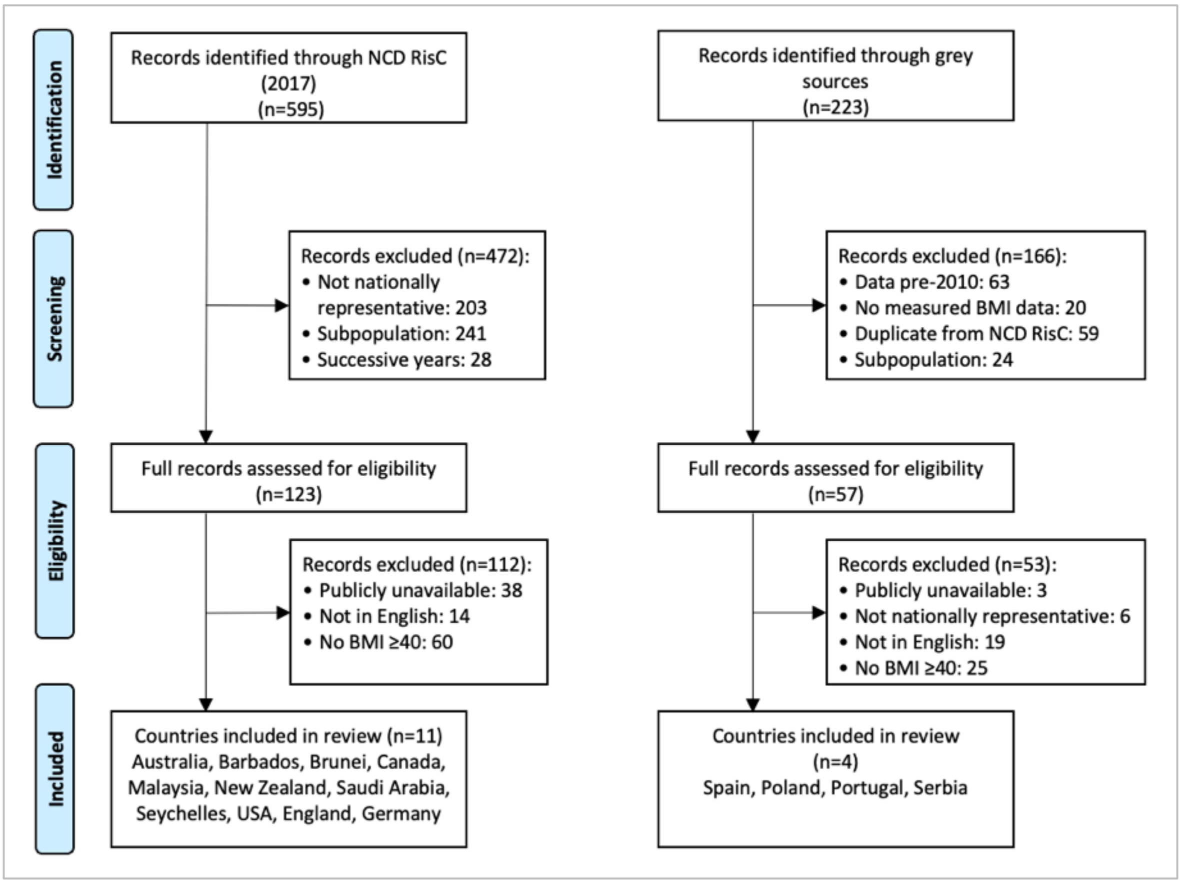


Figure 2.1 Search strategy Part 1 and 2: NCD-RisC sources and grey sources

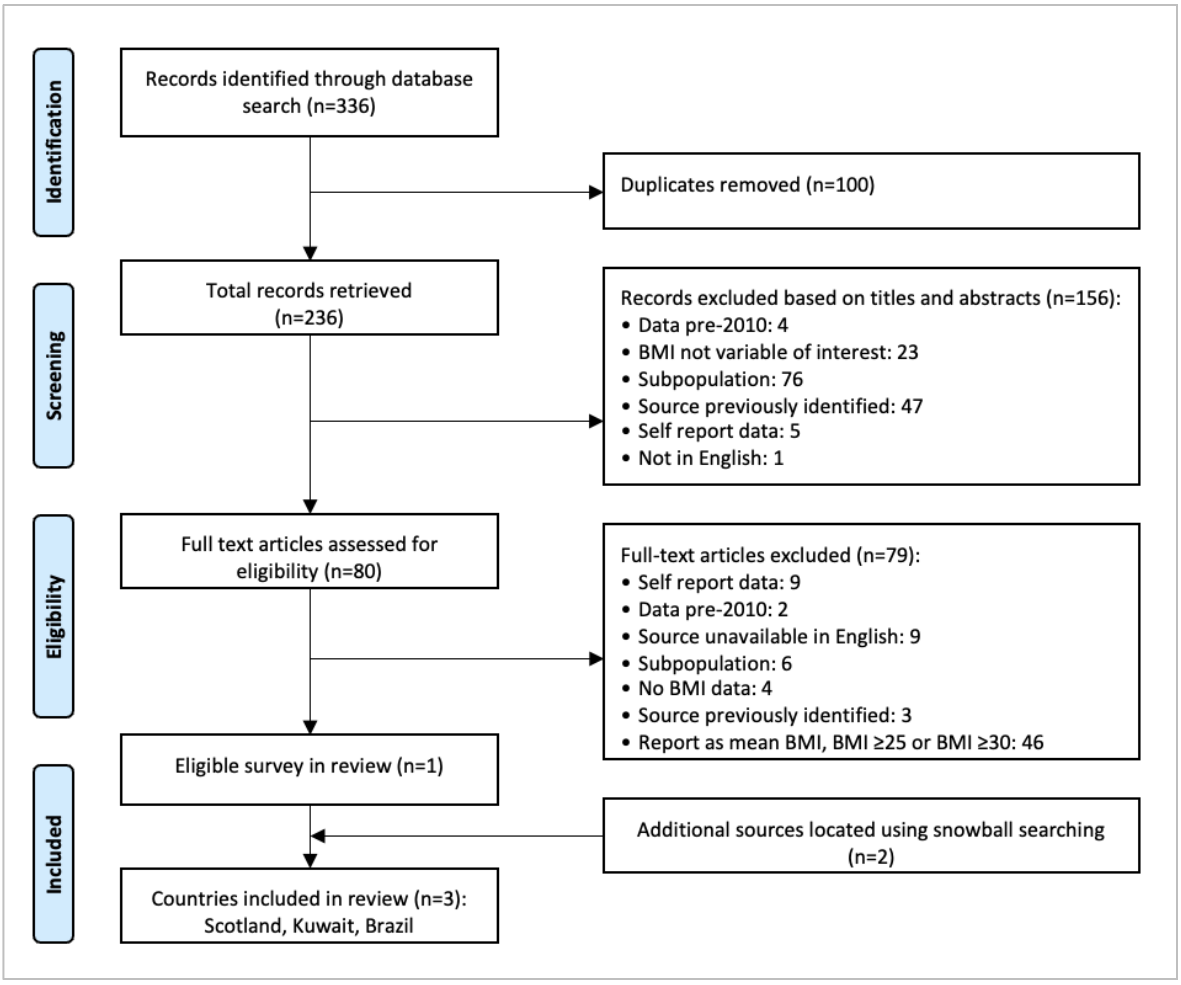


Figure 2.2 Search strategy Part 3 and 4: literature search

2.5 Results

Prevalence data of measured BMI ≥40 kg/m^2 from 2010 onwards were located for 18 individual countries, on all five continents, comprising 12% of eligible national survey data examined (Table 2.2) either in its primary form (*n*=10) or through secondary analysis (*n*=8). Data were very recent, with half of the countries reporting prevalence from 2015 onwards, and only three back to 2010. None of the original sources located reported BMI data categories higher than BMI ≥40 kg/m^2 (for example BMI ≥45/≥50 kg/m^2), with just one secondary analysis from Spain doing so (Aranceta-Bartrina et al., 2016).

Germany (Mensink et al., 2013), Saudi Arabia (Ministry of Health Saudi Arabia, 2013), Seychelles (Ministry of Health Seychelles, 2015), and Poland (Stepaniak et al., 2016) report only for men and women separately, with no data for combined-sex adults. In contrast, only combined-sex-adult data were available for Brazil (Wagner et al., 2019) and Portugal (Gaio et al., 2018). All regions of the world (as defined by WHO) contained a country with rates above 4% for women, and 2% for men, with the exception of Africa, where the maximum was Seychelles with 1.5% for men (Ministry of Health Seychelles, 2015). Other than Brunei Darussalam (Ministry of Health Brunei Darussalam, 2015), rates for women were universally higher than for men.

Prevalence rates are presented graphically in Figures 2.3 to 2.5. The United States has the highest prevalence (Hales et al., 2018), with rates across all adults, men and women ranging between 5.6% and 9.7%. Other countries with higher rates (5.0-7.7%) for all adults and women are New Zealand (Ministry of Health New Zealand, 2019), Kuwait (Weiderpass et al., 2019) and Barbados (Unwin et al., 2015), although rates in men are markedly lower. Australia (Australian Bureau of Statistics, 2019a), Canada (Statistics Canada, 2017), Scotland (Scottish Government, 2018a), England (NHS Digital, 2018a) and Saudi Arabia all have rates in the region of 2.5% to 5.5% for all adults and/or women, again with men notably lower. Germany, Serbia (Jovic et al., 2016), Spain, Portugal, Poland, Brazil and Malaysia (Malaysian Institute for Public Health, 2015) display the lowest rates between 0.7 and 2.8%. Brunei Darussalam and Seychelles both exhibit disparate prevalence patterns from those above for men and women.

Table 2.2 is modelled on Foresight's International Evidence Review (Lobstein and Jackson Leach, 2007), which when published illustrated the general availability of regionally comparative BMI ≥30 kg/m^2 prevalence data. The rigorous inclusion criteria applied during searching means that most sources (with potential exception of Spain and Poland) were from surveys done or supported by national government agencies, with primary reporting through grey literature sources. Due to the constraints associated with gathering measured data, total sample sizes tend to be relatively small, with thirteen countries being <8,000, and five above this. With prevalence under 10% of these numbers, wide confidence intervals result for BMI ≥40 kg/m^2, as seen in Table 2.2.

Table 2.2 International BMI ≥40 kg/m^2 prevalence rates for data collected since 2010.

Country	Prevalence %			Source	Data collected Year	Sample size	Age (years)	Ongoing data collec-tion	Data Collection Method	Scale capacity (kg)
	All	**Men**	**Women**							
WHO European Region										
England	4[a] (3.1-4.1)	2[a] (1.9-3.2)	5[a] (3.9-5.4)	Health Survey England (NHS Digital, 2018a)	2017	6,530	≥16	Annual	Home visit	200
Scotland	3[a] (2.8-4.1)	2[a] (1.5-3.2)	4[a] (3.5-4.5)	Scottish Health Survey (Scottish Government, 2018a)	2018	3,746	≥16	Annual	Home visit	200[b]
Germany	_	1.3 (0.8-1.8)	2.8 (2.2-3.5)	German Health Interview & Examination Survey for Adults (Mensink et al., 2013)	2008-11	7,116	18-79	No	Commun-ity centres[c]	250
Poland	_	1.3 (0.09-1.7)	1.8 (1.3-2.3)	WOBASZ II (Stepaniak et al., 2016)	2013-14	5,417	≥20	No	Home visit and clinics	No data
Portugal	1.8 (1.4-2.2)	_	_	National Health Examination Survey (INSEF) (Gaio et al., 2018)	2015	4,819	25-74	No	Health centres	200
Serbia	1.4 (1.2-1.6)	0.7 (0.5-0.9)	2.0 (1.7-2.4)	National Health Survey (Jovic et al., 2016)	2013	13,103	≥15	No	Home visit	No data
Spain	1.3 (1.0-1.8)	1.0 (0.6-1.6)	1.6 (1.1-2.3)	Nutritional Study of Spanish Population (ENPE) (Aranceta-	2014-15	3,966	25-64	No	Home visit	150

Country	Prevalence %			Source	Data collected Year	Sample size	Age (years)	Ongoing data collec-tion	Data Collection Method	Scale capacity (kg)
				Bartrina et al., 2016)						
WHO Eastern Mediterranean Region										
Kuwait	5.5 (4.8-6.3)	3.9 (2.9-4.9)[d]	7 (5.9-8.1)[d]	STEPS (Weiderpass et al., 2019)	2014	3,589	18-69	No	Health centres	No data
Saudi Arabia	_	2.5 (2.3-3.3)	4.7 (3.9-5.5)	Saudi Health Interview Survey (Ministry of Health Saudi Arabia, 2013)	2013	10,337	≥15	No	Home visit	No data
WHO Western Pacific Region										
Australia	4.0 (3.6-4.4)	3.3 (2.8-3.8)	4.7 (4.2-5.2)	National Health Survey (Australian Bureau of Statistics, 2019a)	2017-18	18,656	≥18	3-4 yearly	Home visit	200
New Zealand	5.1 (4.5-5.6)	3.5 (2.9-4.1)	6.6 (5.8-7.4)	New Zealand Health Survey (Ministry of Health New Zealand, 2019)	2017-18	13,869	≥15	Biennial	Home visit	200
WHO Africa Region										
Seychelles	-	1.5 (0.5-2.5)	6.7 (4.9-8.5)	Seychelles Heart Study IV (Ministry of Health Seychelles, 2015)	2013-14	1,240	25-64	No	Health centre	No data
WHO Americas Region										
Barbados	5.0 (3.7-6.7)	1.8 (0.8-4.0)	7.9 (6.0-10.5)	Barbados Health of the Nation Study (Unwin et al., 2015)	2011-13	1,197	≥25	No	Home visit	No data

Country	Prevalence %			Source	Data collected Year	Sample size	Age (years)	Ongoing data collec-tion	Data Collection Method	Scale capacity (kg)
Brazil	1.8 (1.6-2.0)	_	_	National Health Survey (Wagner et al., 2019)	2013	49,359	20-64	No	Not given	No data
USA	7.7 (6.6-8.9)	5.6 (4.3-7.2)	9.7 (8.4-11.2)	NHANES (Hales et al., 2018)	2015-16	5,337	≥20	Biennial	Mobile Examina-tion Centre[c]	272
Canada	4 (2.8-5.8)	2.6[e] (1.3-5.0)	5.5 (3.9-7.7)	Canadian Health Measures Survey (Statistics Canada, 2017)	2014-15	5,794	18-79	Biennial	Mobile Examina-tion Centre[c]	272
WHO South East Asia Region										
Brunei Darussallam	3.0 (2.2-4.0)	3.9 (2.6-5.6)	2.3 (1.4-3.6)	National Health and Nutrition Status Survey (Ministry of Health Brunei Darussalam, 2015)	2010-11	1,524	≥19	No	Local clinic[c]	200
Malaysia	1.4 (1.2-1.6)	0.9 (0.7-1.2)	1.9 (1.6-2.3)	National Health & Morbidity Survey (Malaysian Institute for Public Health, 2015)	2015	5,196	>18	No	Not given	150

Legend: BMI, Body Mass Index; WHO, World Health Organisation; [a]Reported as rounded, whole numbers only; [b]confirmed through personal communication with survey team; [c]Transport provided to centre if needed; [d]Confidence intervals calculated using % sample size for men and women, as absolute numbers only provided for all adults; [e]source advises use with caution.

Less than half of the countries included have regular surveillance, ranging from annual to three to four yearly (Table 2.2: England, Scotland, Canada, New Zealand, Australia and the United States), significantly limiting analysis of trends over time. Reporting from other countries appears to be more ad-hoc and unpredictable, without planning for regular surveillance.

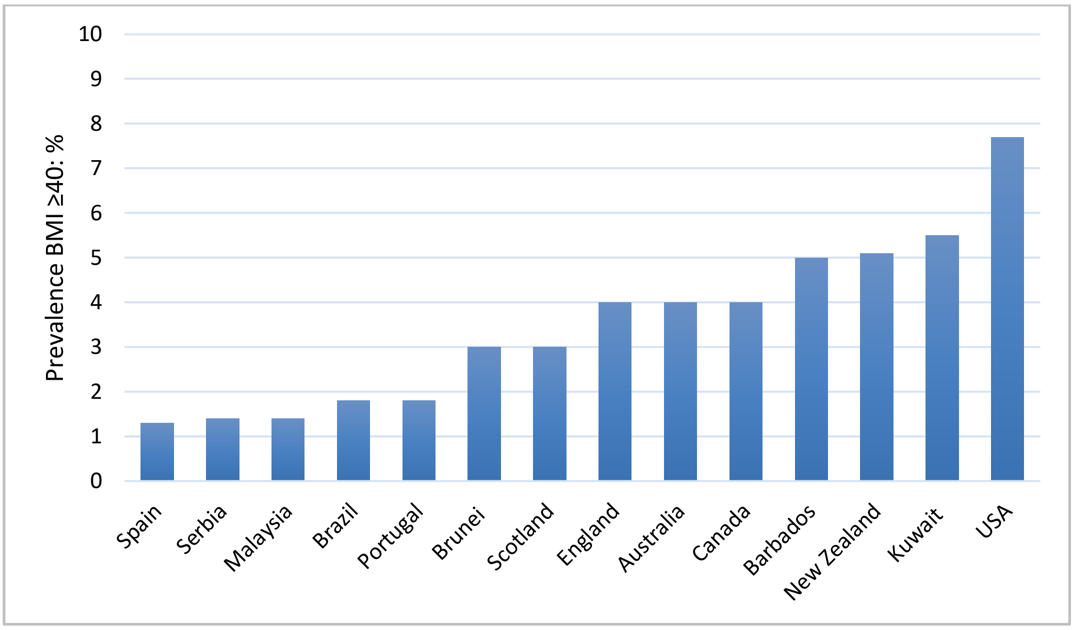


Figure 2.3 International BMI ≥40 kg/m² by country: all adults

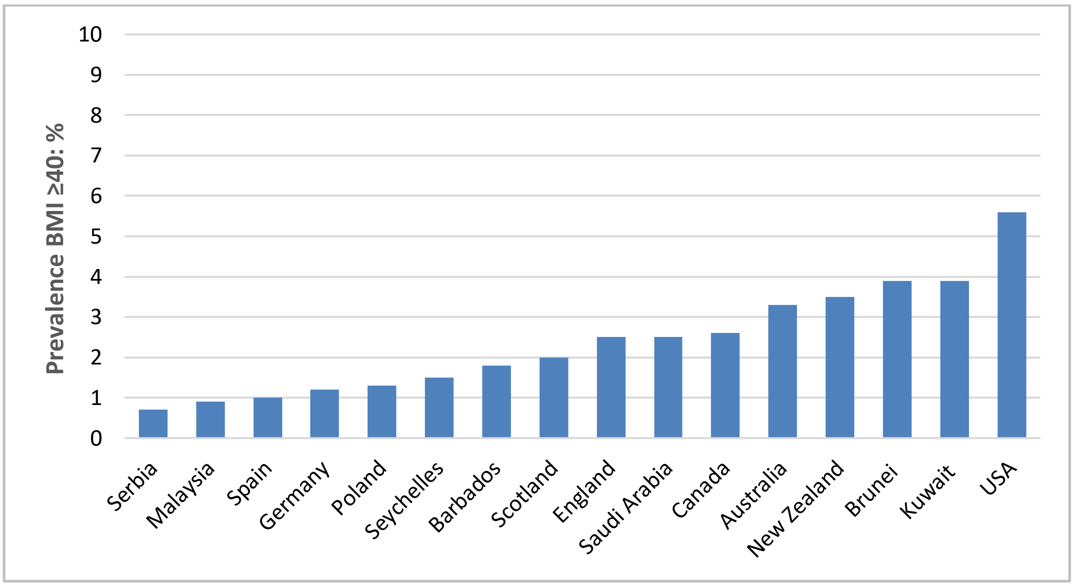


Figure 2.4 International BMI ≥40 kg/m² prevalence rates by country: men

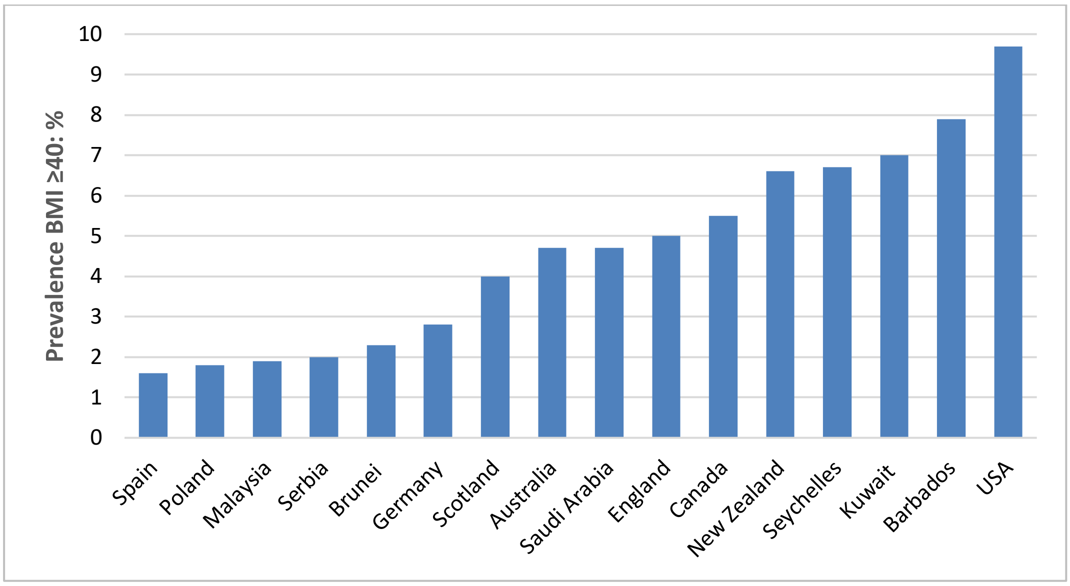


Figure 2.5 International BMI ≥40 kg/m^2 prevalence rates by country: women

2.5.1 International survey data sources

Globally, BMI ≥40 kg/m^2 data were generally poorly available compared with BMI ≥30 kg/m^2 data. Seventy-one NCD-RisC sources had BMI ≥25/≥30 kg/m^2 data available in English, of which only 11 (15%) provided BMI ≥40 kg/m^2 data. Forty six studies out of the 80 screened for the literature search reported mean BMI or BMI ≥25/≥30 kg/m^2 data, with just one (2%) reporting BMI ≥40 kg/m^2. For Africa, only the island state of Seychelles presented BMI ≥40 kg/m^2 data.

The OECD annually publishes country by country Health Statistics with measured data sources for 26 out of 44 countries in its 2019 report (Organisation for Economic Cooperation and Development, 2019a). Many major European countries are missing, as the European Health Interview Survey (EHIS), which is the primary health data collection tool for Eurostat, the Statistics office of the European Union, uses self-reported height and weight data (Eurostat and European Commission, 2013). The European Health Examination Survey does include measured data, but appears not to have been widely adopted (Kuulasmaa and Tolonen, 2019).

Additional grey sources were searched, including WHO website, where the categorisations consistently applied to data were BMI 25.0 to 29.9 kg/m^2 and ≥30 kg/m^2, with no additional categorisation for BMI ≥40 kg/m^2. The WOF website supports the Global Obesity Observatory, featuring a searchable interactive map detailing national overweight and obesity rates, with data sources referenced. All 179 available countries were individually searched, with 12 displaying data on BMI ≥40 kg/m^2 (World Obesity Federation, 2019), of which four had not been previously identified and fitted the inclusion criteria.

2.5.2 Data quality

To enable assessment of data quality the column headers of Table 2.2 highlight basic quality parameters appropriate to national health surveillance (Pineda et al., 2018), with additional categories particularly relevant to the population with BMI ≥40 kg/m^2.

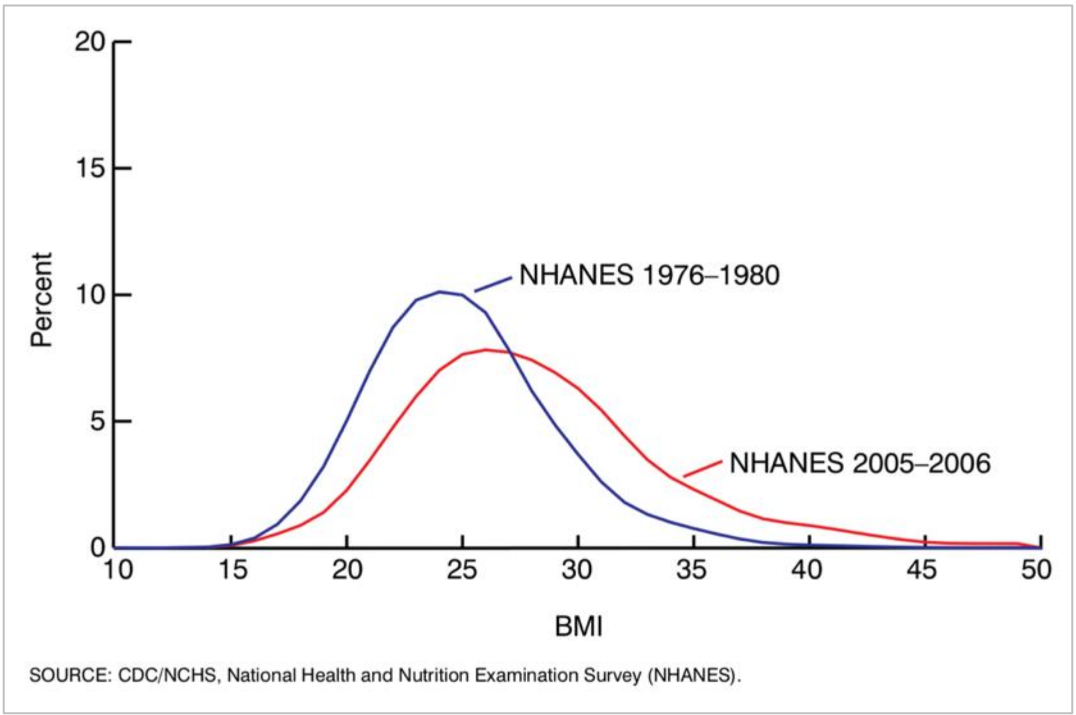
Survey methods for the six countries with regular surveillance in place (England, Scotland, Australia, New Zealand, Canada and the United States) are available for scrutiny on public websites. These surveys employ complex sample design, aimed at reducing bias and with weighting to reflect the age/sex stratification of the population. Response rates are difficult to compare, due to heterogeneity of definitions. As ongoing programmes, the surveys measure nonresponse across years, which appears to be a growing challenge, with Australian data showing the nonresponse rate for the BMI module specifically, increasing from 26.8% in 2014 to 2015 to 33.8% in 2017 to 2018 (Australian Bureau of Statistics, 2019b). Secondary analyses tended to have less available detail on sampling and methodology, with those for Spain (Aranceta-Bartrina et al., 2016) and Brazil (Wagner et al., 2019) referencing previous publications not available in English.

Data collection methods of included surveys were scrutinised for factors that may affect participation of people with BMI ≥40 kg/m^2 (Table 2.2). Eleven countries specifically stated exclusion criteria, which were very similar, namely the institutionalised population. This excluded those in hospitals and, apart from New Zealand, people in care homes. No surveys appeared to document an upper BMI limit, but the capacity of scales used has potential to enact this, effectively meaning individuals with weights over the maximum capacity of the instrument are either excluded or estimated self-reports (NHS Digital, 2018a). No clear data on scale capacity could be found for seven countries, two countries appear to have used scales with a maximum capacity of 150 kg, whilst nine had scale capacities of 200 kg or over. Functional mobility limitations may affect participants' ability to stand on scales or attend examination centres outside the home. For two countries place of anthropometry data collection was unavailable, nine countries used home visits, whilst seven required participants to leave their home, although some of these offered transport if needed.

2.6 Discussion

Whilst good quality BMI ≥30 kg/m^2 prevalence data are now available globally, largely due to the widespread implementation of surveillance tools such as STEPS, there are few robust measured data on BMI ≥40 kg/m^2 or higher categories. The published surveys generally use similar proven methodologies to obtain population-representative data. However, the methods used to assess BMI >30 kg/m^2, risk providing inaccurate results for higher BMI categories, for example if they require mobility of participants or if the scales used have an upper limit of 200 kg. Hence, true prevalence may be higher than stated in Table 2.2.

The data that are available have limitations, notably wide confidence intervals for higher BMI categories, making it difficult to determine the significance of annual changes. If, as predicted, numbers with BMI ≥40 kg/m^2 continue to grow, this problem may diminish, although is unlikely to disappear altogether as the cost of gathering measured data limits sample sizes. The limited long-term trend data available help to overcome uncertainties with large confidence intervals for the smaller numbers with BMI ≥40 kg/m^2. Since 1995, BMI ≥40 kg/m^2 prevalence in Scotland has trebled for women aged 16 to 64 years (Scottish Government, 2018b). Australia saw similar increases of 2.9-fold for men and 2.0-fold for women between 1995 and 2011 to 12 (Keating et al., 2015). Prevalence of BMI ≥40 kg/m^2 in the United States quadrupled between 1976 and 2004, substantially surpassing the rise in BMI ≥30 kg/m^2 (Ruhm, 2007). Prevalence in men in England aged 16 years or older experienced an eight-fold increase since 1995 (NHS Digital, 2018a), but Brazil reported the most dramatic increase of nearly 20-fold between 1974-1975 and 2013 (Wagner et al., 2019). Overall population distributions have thus consistently shifted upwards, as illustrated in Figure 2.6, comparing waves of USA NHANES data from 1967-1980 to 2005-6 (Ogden et al., 2007).



SOURCE: CDC/NCHS, National Health and Nutrition Examination Survey (NHANES).

Figure 2.6 Changes in the distribution of body mass index (BMI kg/m^2) between 1976-1980 and 2005-2006, adults aged 20-74 years: United States.

Legend: Data are age adjusted by the direct method to the year U.S. Census 2000 estimates using age groups 20–39, 40–59, and 60–74 years. Overweight is body mass index (BMI) of 25.0-29.9 kg/m^2; obesity is BMI at or above 30.0 kg/m^2; and severe obesity is BMI at or above 40.0 kg/m^2. Pregnant women are excluded from the analysis (reproduced from Ogden et al., 2007, no permission required).

Comparison with analyses of self-report surveys from the United States and Canada, which allow for much larger samples, all show disproportionately larger growth in higher BMI categories, with increases of up to 10-fold in the BMI ≥40 kg/m^2 category (Sturm and Hattori, 2013, Krishna et al., 2015, Lebel et al., 2018). This is despite suggestions that the underestimation of weight for self-report data is likely to be greater with higher BMI (Luo et al., 2019). Thus, despite wide confidence intervals in individual survey years and some variations in methodologies, measured trend data evidence from several countries, together with larger-scale self-report datasets, all support a long-term rise in BMI ≥40 kg/m^2.

Two key sources of data for NCD-RisC and WOF were STEPS reports and Demographic and Health Surveys (DHS) country reports. The STEPwise approach, featuring three different level of “steps” of key risk factor assessments for NCDs, was developed by WHO, to aid countries increase their surveillance capacity (World Health Organisation, 2017). One hundred and thirteen country reports or data sheets were publicly available on the WHO STEPS site at the time of searching (World Health Organisation, 2019). DHS is supported by the U.S. Agency for International Development (USAID) (Demographic and Health Surveys Program, 2019a), to inform planning particularly in relation to maternal and child health, with over 93 standard DHS reports since 2010 on its website (Demographic and Health Surveys Program, 2019b). Both of these are easily accessible population surveillance tools, widely used by low- to middle-income countries, with standard methodologies including collecting measured height and weight in a household setting. Current standard reporting practice for STEPS & DHS focusses on BMI 25.0 to 29.9 kg/m^2 and ≥30 kg/m^2, with no additional categorisation for BMI ≥40 kg/m^2.

International health surveillance provides reliable health information that is comparable over time and between populations. It has allowed documentation of a nutrition transition that is rooted in the impact of large-scale social changes such as reduction in physical activity, increased urbanisation and greater consumption of processed food (Popkin et al., 2012). Whilst regional variation remains, the major global concern has moved away from underweight as the primary nutrition issue, toward excess weight as the leading cause of morbidity and mortality through secondary non-communicable diseases (Global Burden of Disease 2015 Obesity Collaborators, 2017). This has already occurred to such a degree that BMI ≥35 kg/m^2 in women now surpasses underweight in 165 countries for women and 113 for men (NCD Risk Factor Collaboration, 2016). Yet current national documentation of BMI distribution does not reflect this shift, with the focus still on reporting categories <18.5 to ≥30 kg/m^2, and/or mean BMI, as the DHS and STEPS reports evidence. This historical bias is obscuring the significant changes in higher BMI categories (Weiderpass et al., 2019, Lebel et al., 2018). Without characterising this progression, policy makers and planners are unable to respond effectively to the needs of the population or evaluate the effectiveness of policies.

The example of Kuwait in this review provides a case in point. The original 2014 STEPS report on the WHO website documents the mean BMI and four separate BMI categories <18.5 kg/m^2, 18.5 to 24.9 kg/m^2, 25.0 to 29.9 kg/m^2, ≥30 kg/m^2, without ≥40 kg/m^2 as a distinct category (World Health Organisation, 2019). The

BMI ≥40 kg/m^2 data were later reported by the analysis of Weiderpass et al of the original STEPS dataset, illustrating that the data had been collected but gone unreported (Weiderpass et al., 2019). Table 2.2 shows Kuwait's prevalence rates as second highest only to the USA, providing valuable information regarding BMI population distribution, in a region where no other sources of all adult prevalence were found.

One practical solution would be for WHO and similar agencies to call for data on the BMI ≥40 kg/m^2 population to be included when reporting all anthropometry surveys. The National Child Measurement Programme in England took an equivalent step in 2018, adding severe obesity as a reporting category (NHS Digital, 2018c). Given that the prevalence of BMI ≥50 kg/m^2 is now similar to that of the BMI ≥40 kg/m^2 category about 20 years ago, with some real-world datasets including categories of 50/60/70 kg/m^2 (Moussa et al., 2019b), it may be wise also to include reporting BMI ≥50 kg/m^2, to map future trends. This would hugely increase the amount of BMI ≥40 kg/m^2 data available globally, with little extra cost, given that the data are already collected. For countries with small numbers to report, the need for caution in interpretation would be dealt with in the same way for low numbers in any category, for example underweight.

2.6.1 Causation

The lack of data on BMI ≥40 kg/m^2 trajectories by region, nation, age, sex and class, makes it difficult to explore causation. Improved international data, ideally from longitudinal studies, would promote comparison between countries, taking into account their differing social and economic contexts (Inoue et al., 2018). Together with the emergence of large-scale genome studies looking at the inherited susceptibility to BMI ≥40 kg/m^2 (Khera et al., 2019), reasons for the escalation of high body weight may be more accurately sought. There are some indications of associations with lower socio-economic status in some populations (Keating et al., 2012, Booth et al., 2017), but these patterns require further study. Concerningly, some countries report increasing rates of the highest BMI groups growing for children and adolescents (NHS Digital, 2018c, Skinner et al., 2018), with potential for excess weight to track through into adulthood. This would differ from current patterns, when rates are lower in early adulthood, peaking in middle age (Hales et al., 2020b, NHS Digital, 2018a, Scottish Government, 2018b). Unusually the survey data from Brunei Darussalam showed 19- to 29-year olds having some of the highest rates of BMI ≥ 40 kg/m^2 across the age trajectory (Ministry of Health Brunei Darussalam, 2015).

A lack of prevalence data keeps the population hidden, preventing development of appropriate weight management services to treat this population group, along with comparative analysis of different treatment models and healthcare systems (Grieve et al., 2013). BMI ≥ 35 kg/m^2 with comorbidities or BMI ≥ 40 kg/m^2 with or without comorbidities is a commonly applied threshold for bariatric surgery, yet access to surgery is often very limited (Gulliford et al., 2016, National Institutes of Health, 1998). Evidence on effective alternatives to surgery or prevention is needed, whilst access to traditional services can be difficult for people with BMI ≥ 40 kg/m^2 due to functional disability (Skea et al., 2019). Improved global prevalence data would facilitate work on economic costing of treatment and prevention for the population with BMI ≥ 40 kg/m^2.

2.6.2 Consequences of rise in prevalence

Whilst numbers may appear small in terms of proportion of the whole population, given that these are at national scale, they translate into significant absolute numbers with a large real-life impact on care provision.

2.6.2.1 Health risk and comorbidities

It is well recognized that BMI can be a poor proxy for body fat and, in many studies, waist circumference or evidence-based predictive equations for total body fat are better than BMI for assessing health risk, particularly cardiac and metabolic health outcomes (Tanamas et al., 2016, Han et al., 2019a, Han et al., 2019b, Al-Gindan et al., 2014). Consequently, surveys from the United States, England, Scotland, New Zealand and Australia all measure waist circumference. However, people with BMI ≥ 35 kg/m^2 exceed these cut points, often with a large abdominal fat apron making methods which incorporate waist circumference unlikely to be reliable with very high body weights. Thus, BMI remains the best available simple estimate of body fat at the highest levels. Surveys and studies need to consider data collection methods, particularly scales capable of weighing at least 200 kg, with easily accessible wide and low platforms, ideally offering home visits to facilitate accurate data collection from people with high BMIs. Additionally, a review is needed regarding the treatment of what have historically been seen as Biologically Implausible Values (BIVs), the majority of which have been found to be accurate (Freedman et al., 2015). The definition of BIVs and use of upper thresholds for weight and BMI in research studies requires re-examination in view of the documented shift in population distribution towards heavier BMIs.

Elevated health risk translates into increased prevalence of multimorbidity (co-occurrence of ≥2 conditions) compared with those of normal weight by nearly two (Booth et al., 2014) to seven times (Jovic et al., 2016), particularly for cardiometabolic multimorbidity (Kivimaki et al., 2017). Alongside physical diseases, risk of depression increases with BMI (Moussa et al., 2019a), together with functional disability, with increasing numbers of people with BMI ≥40 kg/m^2 living in care homes (Hajek and Konig, 2017). As such care of these multiple obesity-related consequences amplifies health care costs considerably (Tremmel et al., 2017). Given the rise in prevalence and size of these costs, in addition to older costing studies being limited by BMI thresholds that are now too low, this is likely to become of increasing concern globally.

2.6.2.2 Planning

As an emerging population, people with BMI ≥40 kg/m^2, especially those with BMI ≥50 kg/m^2 and ≥60 kg/m^2, have needs that are currently often unaddressed by service providers (Lumley et al., 2015). Increasingly changes to care environments are being needed to accommodate larger body sizes, requiring adjustments such as widened doorways, reinforced floors, suitable seats, and larger rooms. Problems featured in the health literature demonstrate the scope of challenges, such as evacuation planning (Gray and Macdonald, 2016), diagnostic scanning (Wiles et al., 2017), and positioning during surgery in theatre (Rosenfeld et al., 2013). Documented requirements include staff training (Royal College of Physicians, 2013), specialist equipment provision (Rosenfeld et al., 2013) and development of specialist clinical protocols covering essential areas, such as tissue viability guidance (Cowdell and Radley, 2014). However, issues are not restricted to health care but affect all aspects of life, including specialist housing (Aberdeen City Council, 2018), adapted workplace design (Gyi et al., 2019), larger sized fashionable and safety clothing (Peters, 2015) and barriers to travelling (Flaherty et al., 2019). Projections of future severe obesity prevalence using different datasets agree in predicting continued rises for the foreseeable future (Finkelstein et al., 2012). Current analyses suggest five million living with a BMI ≥40 kg/m^2 in the United Kingdom by 2035, with rates up to 20% for Welsh women aged 55 to 64 years (Keaver et al., 2018) and over 20 million people affected in the United States (Cecchini, 2018). Better characterisation of the population with BMI ≥40 kg/m^2 is required to support organisational and societal readiness for this population. Adaptations are expensive in time and money, particularly when made retrospectively, underlining the need for accurate planning to happen now.

2.6.3 Strengths and Limitations

This review has concentrated on robustly measured data to establish the international prevalence rates for BMI ≥40 kg/m^2. Whilst the rationale for exclusion of self-report data is sound, in that it commonly underestimates BMI, the exclusion also acts as a limitation, for example by excluding EHIS data which covers many European countries. The sample sizes possible with measured data are reduced by the need for resources to make measurements, and there is potential bias against including very heavy individuals whose mobility is impaired. In some cases, the upper limit of scales excluded the heaviest individuals. These limitations would tend to underestimate the true prevalence of the highest BMI categories, not overestimate.

Applying a lower threshold of BMI ≥35 kg/m^2 would have broadened the available data, whilst potentially weakening the focus on the highest BMI category, where cost and clinical complexity is greatest. Some studies report the lower threshold of BMI ≥35 kg/m^2 particularly those examining Asian populations where different BMI cut-offs relating to overweight and obesity are often applied (Wu et al., 2015).

Limiting the review to the English language prevented examination of some original data sources which could only be located in their native language, for example, Spanish for Chile and Mexico. It was not possible to locate English versions of these and resources did not allow for translation. The OECD reports these original sources in English in its database, but only at BMI thresholds of 25.0 to 29.9 kg/m^2 and BMI ≥30 kg/m^2, with prevalence for Chile and Mexico the highest in the world, above even those of the United States (Organisation for Economic Cooperation and Development, 2019b). Thus, they are likely to have significant BMI ≥40 kg/m^2 prevalence. Additionally, whilst the search processes were broad, encompassing a variety of sources and used systematic methods, they were not exhaustive, as might be expected from a formal systematic literature review or meta-analysis. We believe that they represent a reliable summary of the current evidence base on BMI ≥40 kg/m^2. Some individual sources have not been included, notably those from non-English publications, but they are unlikely to alter the very consistent conclusions.

2.7 Conclusion

This review highlights the poor availability of robust international data available on the emerging issue of BMI ≥40 kg/m^2 prevalence. The measured data available suggest significant prevalence on all five continents, with proportionally large rises in recent decades. Given the multiple care challenges, high resource needs and poor current evidence base for this population, routinely reporting BMI ≥40 kg/m^2 and higher categories in national surveys would be valuable, with appropriate caveats for interpreting the still small numbers in individual surveys. Accurate characterisation of the subpopulations with BMI ≥40 kg/m^2 and higher categories requires consideration of measurement equipment and the mobility limitations of individuals with high BMI.

Chapter 3 Methods Navigating data governance approvals to use routine health and social care data to evidence the hidden population with severe obesity: A case study from a clinical academic's perspective

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Contributions: I undertook all the applications for approvals, liaising with all stakeholders, with input from supervisors. In response to approval requirements, along with supervisors I evolved study design. I wrote the initial draft manuscript, with edits from supervisors (MEJL, AN and DNB). I took the lead in manuscript submission and responding to reviewer comments, with input from my supervisors.

3.1 Overview

To answer all the research questions a retrospective, cross-sectional observational mixed-methods study was designed. It was deliberately non-interventional, focussing on characterising the community-dwelling population with BMI ≥40 kg/m^2, particularly those using the most community health and social care services, in terms of dose of care intensity, length of episode and number of services and who, by definition, may be housebound.

As a practising clinician, the author was aware of where routine data relating to community health and social care services were recorded, aiming to use these data sources in study design. However, accessing these data sources for the study's purposes was more complex than anticipated (Williamson et al., 2022c). This was partially due to timing, as seeking approvals coincided with the introduction of the European Union General Data Protection Regulation in 2018.

Consequently, even experienced approvers were navigating unfamiliar territory, with supportive resources not yet developed. It also reflected the cross-sector, interdisciplinary nature of the subject, in not being limited to one service or comorbidity of interest. Thus, the data governance context and requirements heavily influenced study design and are key to understanding some of the decisions taken by the study team.

Due to the complexities of the data governance landscape and delays experienced, general practice data were excluded from the study. The author undertook some work separately to the current study, looking at recording of BMI by GP practices within the local authority area which hosted the study. Outcomes were broadly similar to those found in the scoping data highlighted in Chapter 1, and published data (Booth et al., 2012), with significant amounts of missing data. Thus, analysis of the BMI dataset available from GPs presents a validity problem for research. The social care records accessed for this study had no dedicated field for BMI, with level of obesity recorded either in free text boxes or under medical history. Therefore, the significant limitations of the routinely-collected data outlined in this chapter, indirectly produced answers to research questions 1 and 2:

1. How many people known to health and social care services have a current BMI ≥ 40 kg/m^2?

2. How many of these are known to be housebound or in care?

Whilst the data governance landscape was complex, the authors were fortunate in having professional links that facilitated a single Health and Social Care Partnership (HSCP) hosting the study. To protect participant confidentiality, this HSCP is not named directly. As the HSCP was aligned with a local authority (further detail on configuration of integrated services is given in the main paper), this made for a well-defined population, facilitating the sampling and data collection process.

Further details of the study's methodology are detailed in the relevant individual chapters/published papers, under Methods sections, hence are not repeated here.

3.2 Abstract

Background

Front-line professionals are uniquely placed to identify evidence gaps and the way routinely-collected data can help address them. This knowledge can enable incisive, clinically-relevant research.

Aim

To document an example of the real-world approvals journey within the current NHS/Higher Education regulatory landscape, from the perspective of an experienced nurse undertaking doctoral study as a clinical academic.

Methods

An instrumental case study approach is used to explore the approvals process for a mixed-methods study. Relevant context is highlighted to aid understanding, including introduction of the General Data Protection Regulation and the integration of health and social care services.

Results

Formal approvals by nine separate stakeholders from four different organisations took nearly three years, including fifteen initial or revised applications, assessments, or agreements. Obstacles included: conflicting views on what constitutes ‘research’ or ‘service evaluation’; isolated decision-making; fragmented data systems; multiple data controllers; and a changing data governance environment. The dual perspectives of being both clinician and academic using routine data are explored.

Conclusions

Practitioners face a complex approvals process to use data they routinely collect for research or evaluation purposes. Use of data during the Covid-19 pandemic has demonstrated the need for streamlining of data governance processes. Practical recommendations are outlined.

3.3 Introduction

"Some groups suffer because their experiences are not made visible in the data" (Steventon, 2020). Front-line care professionals[1] can identify priority areas for practice development and research (Carrick-Sen et al., 2016), which may be unseen by policy makers, senior managers and academics. Practitioners routinely process data to enable care, providing a familiarity with at least some of what is held in multiple care systems. Increasingly routine data are recognised as potentially rich data sources for answering research questions (Heslop et al., 2020), whilst opening innovative horizons for both care delivery and research (Scobie and Castle-Clarke, 2019). Yet professionals, particularly Nurses, Midwives and Allied Health Professionals (NMAHPs), can face numerous barriers to engaging in research (Marjanovic et al., 2019) whether experimental, observational or service evaluation.

Clinical academic roles, with both clinical and research components, address the twin problems of researchers struggling to engage over-burdened clinical staff (Sheard and Peacock, 2019), and poor translation of research findings into real-world care (Carrick-Sen et al., 2016). This case study explores the recent real-world experience of a NMAHP clinical academic planning a service evaluation, including accessing routinely-collected health and social care data, to document a population which is "not made visible in the data". The overall aim being to improve the evidence base to support future service improvements and research (Finch, 2009).

3.3.1 Care for housebound adults with severe obesity

The evaluation originated from the first author's role as a senior community nurse, caring for escalating numbers of housebound adults with severe obesity (body mass index (BMI) ≥ 40 kg/m^2). This population experiences poor clinical outcomes from multiple disabling physical and mental health conditions. Skin breakdown is common, aggravated by type 2 diabetes and lymphoedema, but minimal evidence exists to guide clinical practice (Williamson et al., 2020). Since the early 2000s, the author had experienced more individuals presenting

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[1] the terms "care professional" or "practitioner" are intended to represent both health *and* social care professionals.

with increasingly complex care needs including tissue viability, incontinence, immobility, and inability to self-care. Locally, a professional forum discussed relevant service developments with managers, who requested quantitative evidence to support a business case justifying change and scoping possible solutions. Subsequent searches to gather local quantitative data, or indeed published national research findings, found little evidence, especially relating to housebound individuals with high BMI and their use of community services (Williamson et al., 2020). Having identified an orphan area of both practice and research, an evaluation systematically detailing the existence of this growing population was planned. EXploring the PREvalence, Service utilisation and patient experience of Severe Obesity (EXPRESSO) planned to use mixed methods gathering quantitative data including height, weight and BMI, plus community health and social care services used. Nested qualitative work sought participants' views on services used. As a purely observational study, no weight management intervention was included.

The local NHS organisation actively promoted research capacity-building for NMAHP staff, supporting the author to undertake the project as a part-time doctorate. This paper documents the process of gaining approvals for EXPRESSO, not outcomes of EXPRESSO itself.

3.4 Methods

A case study approach was applied to the approvals process, to gain "an in-depth, multifaceted understanding of a complex issue in its real-life context" (Crowe et al., 2011, p1). Such a case study is considered instrumental (aiding broader understanding of an issue) (Crowe et al., 2011) in that elements of this approvals process will be familiar to many researchers generally (Snooks et al., 2022). However, the real-world experience and context is infrequently documented, forgoing valuable learning, particularly for novice researchers. Thus, lessons learnt have relevance for:

1. professionals considering service evaluation, audit, or research;
2. regulatory authorities and
3. data analytic workstreams.

Key questions of how, what and why were used to structure exploration of the case study (Crowe et al., 2011). “How” was interpreted as the processes undertaken to gain the necessary approvals, evidenced though numbers of applications, communications and clarifications, and is reported in the Results section. “What” relates to specific governance requirements, such as Ethics and Caldicott processes, outlined under Context. “Why” highlights wider regulatory context, detailed in Context and Discussion sections.

3.4.1 Context

Defining the context of a case study is critical to understanding it, alongside its relevance or not, to other cases (Brogan et al., 2019). Thus, pertinent contextual information is provided here. The timing of this case study was significant, spanning a period of substantial change for care sector governance, including adoption of the European Union General Data Protection Regulation (GDPR) in May 2018 (Table 3.1). GDPR governs processing of all personal data, giving individuals control of their data (Information Commissioner's Office, 2021).

Additionally, as elsewhere, Scotland has adopted a policy of health and social care integration through legally establishing Health and Social Care Partnerships (HSCPs) from April 2016. Comprising members and devolved budgets from constituent NHS and local authorities, HSCPs take responsibility for adult social care services, adult primary care, community health services and designated hospital services (Burgess, 2016).

Early EXPRESSO design involved searching Electronic Health Records (EHRs) of three to five General Practices (GPs) for individuals with recorded BMI ≥40 kg/m^2. Data known to be recorded in GP and wider NHS EHRs (Table 3.1) included number and type of services used and length of care episode, enabling some basic health economic costing. Caldicott approval is based on principles summarised in Table 3.2 and is essential for projects using NHS and social care data.

Initial Caldicott approval stipulated use of a local NHS Safe Haven for data processing. Unfortunately, the associated unfunded cost (£2,000+) made this unviable. Safe Haven usage would have potentially simplified subsequent data processing by preventing the need for data transfer beyond the NHS. However, data access issues would have remained, as relevant datasets were not already within the Safe Haven.

Table 3.1 Health and Social Care datasets in Scotland[a]

Datasets	Purpose of access for clinical role	Specific data of interest for study	Data controller	Legal requirement for data gathering/ sharing[b]	Legal Responsibility for sign off
GP data (e.g., VISION/ EMIS, Micro-test)	1. General Practice care record; 2. Prescribing; 3. Assessing home visit risk; 4. Holistic person assessment[c]	1. Height, weight, BMI 2. Medications 3. Coded comorbidities	Individual GP practice	DSA signed off by Caldicott Guardian & GP practice	1. NHS Caldicott Guardian 2. GP practice
Trakcare (most NHS services)	1. Recording inpatient & outpatient hospital data 2. Can link to other systems e.g., ELMS[d]	1. Height, weight, BMI 2. Outpatient/ community health episodes of care	Health Board via Caldicott Guardian	Permission from Caldicott Guardian	3. NHS Caldicott Guardian
Social Care (SWIFT, MOSAIC, Care First)	1. PoC provision 2. Occupational Therapy input 3. Social work input	1. PoC provision 2. Occupational Therapy input 3. Social work input	Local Authority or since integration, delegated authority via HSCP.	DSA signed off by Caldicott Guardian and Local Authority or HSCP manager.	4. NHS Caldicott Guardian 5. HSCP senior manager

Legend: BMI-Body Mass Index; DSA-Data Sharing Agreement; HSCP-Health and Social Care Partnership; GP-General Practitioner; PoC-Package of Care; [a]broad principles-specifics may vary by region; [b]identifiable data for purposes other than enabling care; [c]including allergies, next of kin, key safe number; [d]Equipment Loan Management Service;

Table 3.2 Summary of Caldicott principles and the General Data Protection Regulation (GDPR)

Caldicott Principles[a]	GDPR
Justify the purpose	Purpose limitation
Only use personal information if it is absolutely necessary	Data minimisation
Use the minimum data required	Data minimisation
Access on a strict need-to-know basis	Data minimisation
Everyone with access to personal data should be aware of their responsibilities	Lawfulness, fairness and transparency
Comply with the law	Lawfulness, fairness and transparency
Duty to share information where needed	Integrity and confidentiality
	Accuracy

Legend: [a]A Caldicott Guardian is a senior individual responsible for data confidentiality within NHS and local authorities, by applying the Caldicott principles to ensure data is used properly. This covers data access, collection, storage, transfer, and disposal.

Though the NHS lacks funding for service evaluation or research, it benefits from service providers cooperating on strategic priorities, such as excess weight. Thus, study design evolved with key collaborations:

1. Local Intelligence Support Team (LIST) providing data analytics (Public Health Scotland, 2020);

2. A GP practice cluster providing a population and

3. NHS Information Technology (IT) staff for data extraction.

LIST staff, Caldicott Guardian and the author met to discuss governance requirements, precipitating a second Caldicott application with amended study design (Figure 3.1) of two different workstreams: one exploring population-level data linkage, the other documenting individual-level data. As a doctoral study, limited data transfer to the University for supervision of analysis was essential. Caldicott approval required strict conditions on all aspects of processing to protect participants’ sensitive data.

Subsequent consideration by local NHS Research & Development staff and the Scientific Officer for the Regional Ethics Committee (NHS REC) deemed the project service evaluation rather than research, recommending organisational approval via the NHS Quality Improvement route.

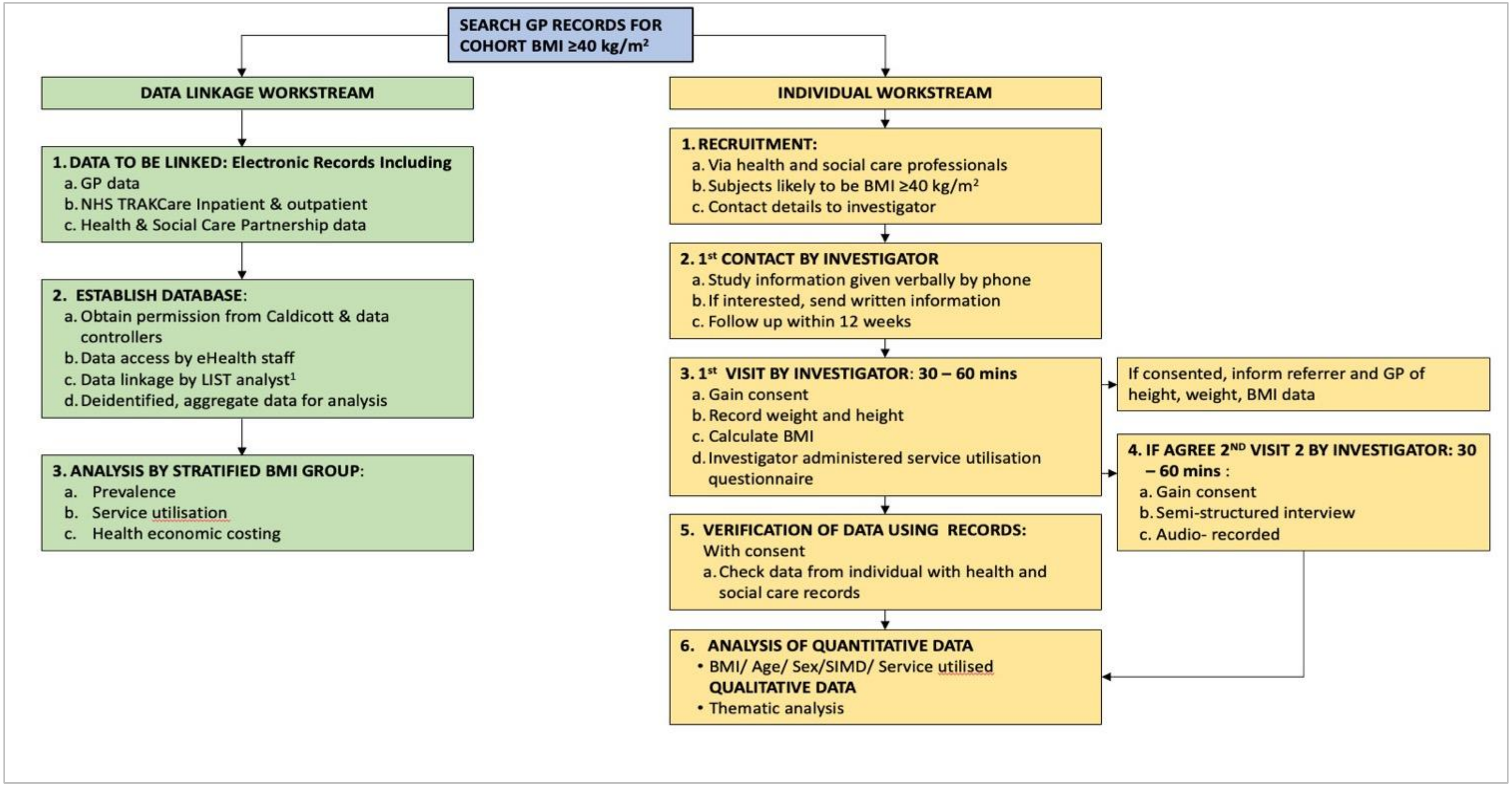

Figure 3.1 Study design February 2018

Legend: Workstream 1 (green pathway): population-level data; Workstream 2 (yellow pathway): individual-level data; [1]Local Intelligence Support Team.

3.4.2 Multiple data controllers

Individual organisations control the data they record. Whilst not essential, Data Sharing Agreements (DSAs) are good practice for data sharing between organisations (Information Commissioner's Office, 2021). They aid compliance with GDPR principles (Table 3.2), stipulating use of a Data Protection Impact Assessment (DPIA) where necessary. DPIAs give a framework for assessing risk regarding data processing. As with a DSA, they require review and sign off by Information Governance staff and senior managers, in addition to investigators. A thorough DPIA was undertaken, with supportive scrutiny from Data Protection staff, particularly regarding Data Protection Information for participants.

Whilst Health and Social Care services are termed “integrated”, current common practice is a “patchwork quilt” (Deeny and Steventon, 2015) of individual data systems between NHS, local authority, third sector and independent partners. Historically these systems are problematic to integrate without major redesign and investment, thus are retained separately. Consequently, individual negotiation is required with each independent data controller regarding data sharing.

3.5 Results

Obtaining all necessary approvals took nearly three years part-time work, with two distinct “active” phases: June 2017 to May 2018 and March 2019 to February 2020. Figure 3.2 provides a visual timeline of key actions and dates March 2019 to February 2020.

In workload terms this represented at least:

1. 15 applications/re-applications/requests/agreements for review and sign off from nine separate stakeholders (Table 3.3);

2. 20 face-to-face meetings and

3. 225 sent emails.

Although Table 3.3 delineates stakeholders by organisation or role, even when stakeholders were within the same organisation, they largely acted independently of each other. The most challenging areas to agree related to data sharing and transfer between organisations.

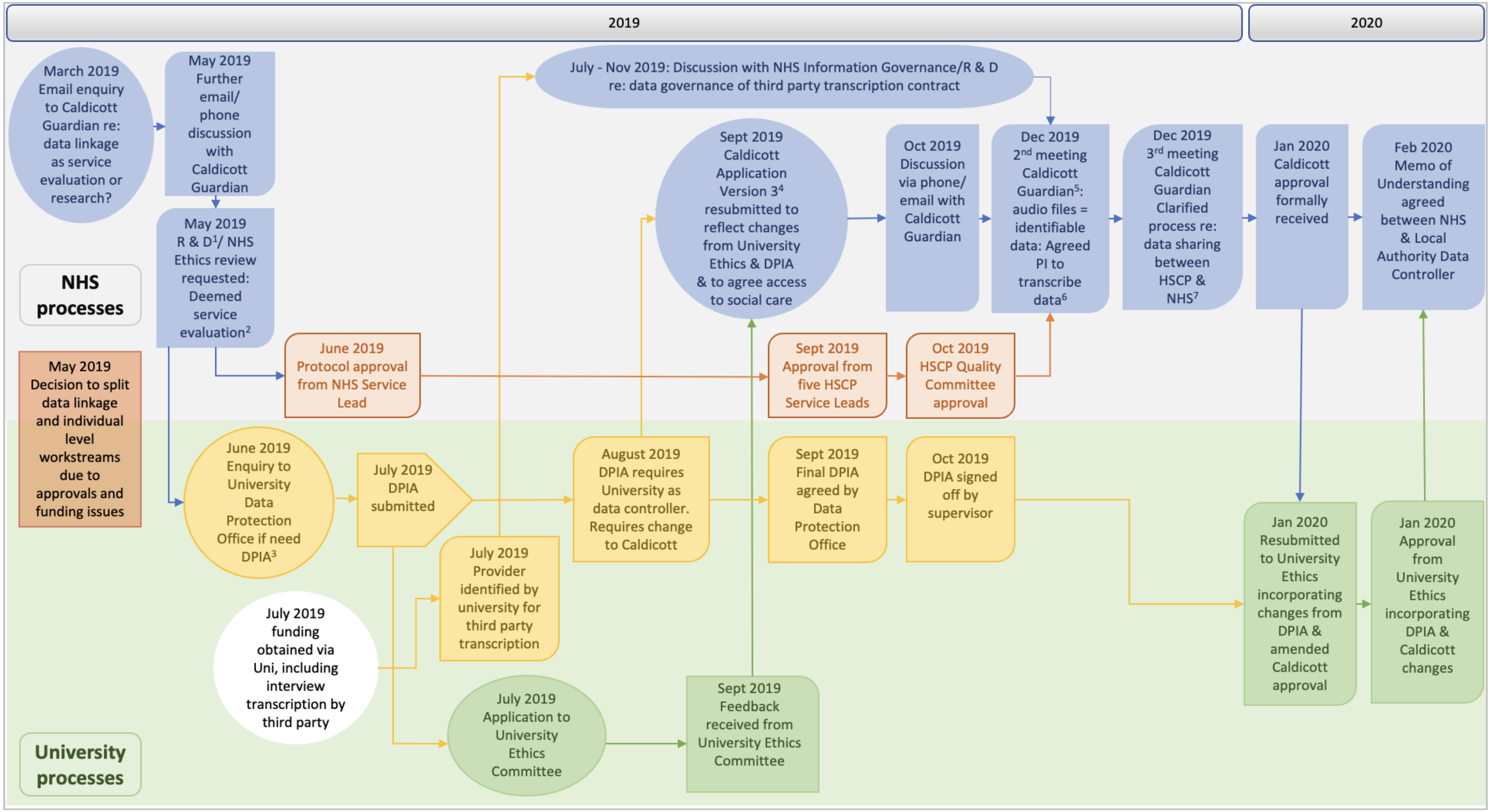

Figure 3.2 Timeline of key actions and dates of approvals March 2019 to February 2020

Legend: [1]Research and Development Office; [2]meaning not requiring NHS Ethics approval instead to follow University Ethics approval route; [3]Data Protection Impact Assessment; [4]Previous two versions pre-March 2019 so not included on timeline; [5]previous meetings pre-March 2019 so not included on timeline; [6]three-way contracting of third party transcription between NHS, University and third party involved potentially complex data processing threatening further delay; [7]service evaluation required assessment of overall population size but lack of shared identifiers for health and social care data gave potential for inadvertent double counting: agreed to collection of minimum dataset from both health and social care staff to exclude this.

Table 3.1 Stakeholders involved in required project approvals.

Approver	Organisation	Status	Procedure
Caldicott Guardian	NHS	Approver/ Data controller	Application
Research Ethics Committee	NHS[a]	Approver	Protocol review by officer, prior to application if needed
NHS Research & Development	NHS	Approver/ Sponsor	Protocol review by officer, prior to application if needed
NHS Quality Improvement	NHS	Approver	Protocol review & application
NHS Service Lead	NHS Care Provider	Data controller/ Sponsor/Risk Assessor	Protocol review
University: Ethics Committee	University	Approver/ Sponsor	Application & Protocol review
University: Data Protection Office	University	Data controller/ Risk Assessor/ Advisor	Study data protection documents & Data Protection Impact Assessment
Health and Social Care Partnership	Joint local Authority/ NHS Care provider	Data controller	Data Sharing Agreement/ Memorandum of Understanding
General Practices	Contracted NHS Care Provider	Data controller	Data Controller Approval letter/Data Sharing Agreement

Legend: [a]Via the NHS Health Research Authority

Extensive clarification was required about how to overcome lack of common identifiers between care providers and ensuring de-identification of data, both written and audio. Ongoing funding applications secured monies for transcription of qualitative, audio-recorded interview data. However, difficulty in identifying a provider with adequate data governance to satisfy the different data controllers threatened unacceptable time delay, prompting the lead author to agree to personally undertake transcription to enable the project to proceed.

Ultimately, complexity surrounding approvals contributed to separation of the two workstreams in Figure 3.1, allowing approvals to progress independently of each other, assuring progression of the doctoral study. The individual data workstream used consented data, simplifying data processing arrangements by removing the need for full data sharing agreements between data controllers. Downstream data governance requirements included setting up of secure shared drives for data storage, with registration of information assets, all in addition to the above workload summary.

Factors contributing to the protracted approvals process were:

1. Delayed responses from key approvers, whose high workload extended timescales;
2. Negotiation with multiple data controllers creating a cyclical process, as changes required by one meant revisiting approvals already obtained and
3. Normal evolution of a research project with study design developing in response to:
    a. comments from approvers;
    b. collaboration opportunities and
    c. funding obtained.

3.6 Discussion

The journey from being a front-line professional daily processing individual patient data, to gaining access to health and social care datasets for evaluation purposes, was longer and more complex than originally anticipated. Obesity research often concerns a single associated comorbidity, such as diabetes, or arthritis. Whilst this helps understanding of specific disease processes, it largely ignores the broader, lived experience of people with excess weight and the delivery of care by community staff. Despite holistic, person-centred care being extolled in health and social care (The Health Foundation, 2016), this project illustrates the challenges of gathering cross-sector data about the “whole person” rather than a single-service or disease focus.

Complex healthcare interventions often need similarly complex evaluations, combining quantitative data analytics framed by local qualitative intelligence (Witham et al., 2015). This case study emphasises how current organisation of health and social care data systems inhibits whole system data collection on individuals. A key example is that different identifiers may be used in health and social care systems, impeding linkage (Scobie and Castle-Clarke, 2019). Such issues are solvable, for example, by seeding health or social care records with a common identifier (Witham et al., 2015), but it places further burden on staff, creating barriers to effective linkage (Heslop et al., 2020).

Encouragingly, stakeholders relatively quickly agreed in principle to share data. Delay occurred when specific technical guidance was sought from approvers. This was partly from GDPR requirements causing a high workload for approvers, producing significant bottlenecks. Additionally, the changing data governance context meant that practical tools, such as draft templates for DSAs or Memoranda of Understanding, were largely unavailable. Since this research began, the Scottish Information Sharing Toolkit (Scottish Government, 2019), and a national Data Sharing Code of Practice (Information Commissioner's Office, 2021) have been published, but initial progress on supportive tools was slow.

3.6.1 Strengths and Limitations

This project incorporated multiple strands: cross-service evaluation as a basis for person-centred quality improvement, alongside research capacity building for NMAHPs through doctoral training. On paper this was a strength, with multiple desirable elements that gave a more comprehensive understanding of the problem. Conversely in practice it was a limitation, as conflating these elements appeared confusing, even conflicting, for approvers. The United Kingdom’s Health Research Authority (HRA) decision tool (Health Research Authority, 2020b) aims to definitively classify research, yet in practice the separating line between service evaluation or research can be very fine (Committee on Publication Ethics (COPE), 2017), with approvers appearing to interpret the guidance differently. Decisions regarding project classification were often fragmented, with approvers focusing on particular aspects of the project. Collection of service level data, including client experience and lack of an intervention, led some to deem it service evaluation. Many service evaluations focus on the quality of an individual service (Twycross and Shorten, 2014). Yet lack of previous evidence, together with the observation from clinical practice, meant the aim here was on defining the current level of service provision across sectors (Twycross and Shorten, 2014). Whilst outcomes will undoubtedly inform local decision-making, the paucity of evidence in this area and the robust methodology applied, particularly to costings, mean that they are potentially indicative at a wider level. This provided substance for a doctoral research study, with findings informing the need for further research in this area, and feasibility of reaching this population. Subsequently the duality of being both a service evaluation and a PhD study has made presentation of the project to other parties more difficult. Specifically this concerned requiring transparency that approvals are for service evaluation, whilst recognising that outcomes may be of interest beyond the local area, thus warrant publication.

Undoubtedly some of the learning from this case study was from experiences common to any novice researcher. Although different projects may face diverse governance challenges, wider evidence indicates that the complexity of the health and social care data environment is challenging for many individuals and organisations involved (National Data Guardian, 2020, Higgins and Matthews, 2020). Users of the Public Benefit and Privacy Panel for Health and Social Care (PBPP), which offers a governance framework for national data, report similar uncertainty and delay in accessing datasets (Lemmon, 2020).

A consultation by the National Data Guardian found staff often feel daunted in achieving compliance (National Data Guardian, 2019) with “bewildering” requirements (Scottish Government, 2019) making staff fearful of blame for inappropriate sharing and feeling underconfident in data governance (National Data Guardian, 2019). Most recently, Health Services Research UK found governance challenges actually deter valuable research, recommending stream-lined processes for low risk/non-interventional studies (Snooks et al., 2022).

3.6.2 Wider application

Despite huge amounts of data within the UK NHS and social care systems, data-driven innovation is not a panacea without difficulties. The Covid-19 pandemic has highlighted the underdeveloped state of social care analytics, with rudimentary data from care homes and domiciliary social care and both analytic capacity and capability disadvantaged (Bardsley et al., 2019). Data quality, particularly missing data, is a concern (Bradley et al., 2018, Higgins and Matthews, 2020). Steventon's (2020) observation that "some groups suffer because their experiences are not made visible in the data", highlights the plight of sub-populations, such as users of social care or people with severe obesity, rendered invisible through lack of reported data. Missing data tells a story precisely due to its missingness.

Practitioners can potentially offer insights from their "tacit knowledge" of data collection and recording into reasons for omission (Witham et al., 2015: p236). For people with severe obesity, it can be as basic as lacking suitable scales for weighing people above 130 kg or who cannot stand. Such learning is vital if data quality and subsequent analysis is to be optimised.

Failure to establish public confidence in appropriate security and relevant usages (aside from immediate care provision) has contributed to the collapse of national health data linkage projects (Heslop et al., 2020). Thus having robust research ethics and data governance processes matters to enable public confidence. Although complexity makes public understanding of data usage a challenge, acknowledged as a priority by the National Data Guardian (2019). Platform-level approaches, such as Safe Havens (Witham et al., 2015, Higgins and Matthews, 2020) and DataLoch (Usher Institute, 2020) as opposed to a project-level approach, offer a potential solution to data storage and security concerns and are being developed more widely (Heslop et al., 2020). However, evolution of these platforms takes time as they also navigate governance and dataset access hurdles. Furthermore, they can require significant funding (Higgins and Matthews, 2020) which may be difficult for smaller exploratory projects such as presented in this case study.

Wider solutions, such as Learning Health Systems (Scobie and Castle-Clarke, 2019) and the Health Foundation's Improvement Analytics Unit (Bardsley et al., 2019), advocate building strong collaborations. These aim to have practitioners, public representatives, analysts, and data governance staff all contributing essential components for using routine data to improve care. Regrettably many practitioners are overburdened by service demand and are infrequently available for collaboration (Sheard and Peacock, 2019) or simply lack mutual spaces to engage.

This case study observes some interesting paradoxes worth noting by practitioners seeking to evaluate routinely-collected data. Firstly, being a registered professional bound by confidentiality, has minimal relevance when seeking approvals. This is because of the key difference in use of the data. If one is a direct care-provider to an individual or population, with necessary access to identifiable data, approvals for use in evaluation may potentially be more straightforward. However, here practitioners face a tension. From an evaluation perspective, direct involvement in care could lead to evaluation bias. Using a different cohort to position oneself outside the direct care team may reduce the risk of bias, but likely makes gaining of approvals more complex. Secondly, high-level approvers may possess expert data governance knowledge, but less applied knowledge of specific data systems. Consequently, practitioners can find themselves guiding approvers through the anomalies of different data systems (such as lack of common identifiers) to ensure that approvals, as given, are workable. Otherwise, it can mean revisiting approvals later, involving further delay.

The principles addressed here, in navigating a piece-meal approvals process for data governance within local government, healthcare and social care systems, are met in similar form internationally. No equivalent case report appears to have been published to critique the processes. However, comparable issues are echoed in recent reports from Europe (Haneef et al., 2020) and Australia (Palamuthusingam et al., 2019) that cite complex data governance as a barrier to data linkage for public health surveillance and research.

3.6.3 Impact of Covid-19 pandemic

Data analytics have been central to the Covid-19 pandemic response, enabling near real-time data on the virus and its impact on populations. Given the global health emergency, approvers have fast-tracked applications for Covid-19 research, with the Secretary of State for Health and Social Care even simplifying processing of data without consent for a limited time (in England and Wales) (Health Research Authority, 2020a). Thus, many challenges have been circumnavigated by stakeholders meticulously working together to facilitate rapid approvals. Despite this, complexities around consent and data sharing remain, with the UK Government breaking the law by not undertaking a DPIA for the Test and Trace system (Marsh and Hern, 2020) and prestigious medical journals being forced to retract articles due to data sharing concerns (The Lancet Digital Health, 2020). Such high-profile errors by well-resourced, expert organisations, underline the convoluted intricacy of the data governance context that now exists. They exemplify why simplified guidance, such as that issued by NHSX, is helpful (Newbury, 2021).

3.6.4 Recommendations

Specific issues for consideration to improve clinical research and service evaluation include:

1. Develop further training due to the technical complexity of current data governance context.

2. Promote toolkits such as the Scottish Information Sharing Toolkit and Data Sharing Code of Practice, including standard templates for DSAs.

3. Encourage early, exploratory conversations with approvers regarding data governance aspects of study design.

4. Improve resourcing of approvers: recognising the increased workload as data governance has gained complexity, so reducing waiting times for approvals.

5. Establish clear lines of information sharing between data controllers, particularly where sharing for service benefit.

6. Develop unified submission approach to clinically-led research and service evaluations across NHS and partner organisations.

7. Promote clinical academic status in healthcare workforces, to release the full potential of routinely-collected data.

8. Facilitate collaborations with practitioners in data projects.

3.7 Conclusions

For practitioners choosing to conduct evaluation and/or research, negotiating access to the data they routinely process can be an arduous process. Despite health and social care service integration in name, governance for health and social care data is complex and fragmented. Technically complicated data governance presents a significant barrier to enabling stakeholders to fully utilise linked data, contributing towards a risk-averse climate within relevant organisations. Yet changes wrought by the pandemic may help with striking a better balance between fully utilising data to improve care and respecting individuals’ rights.

Chapter 4 Results Challenges in obtaining anthropometric measures for adults with severe obesity: A community-based study

This chapter is published in the Scandinavian Journal of Public Health (Open Access).

Williamson, K. Blane, D.N., & Lean, M.E.J.(2022) Challenges in obtaining anthropometric measures for adults with severe obesity: A community-based study. Scandinavian Journal of Public Health, 51,6, 829-971.

Contributions: I undertook participant recruitment, data collection, analysis and interpretation with guidance from my supervisory team. I wrote the initial draft manuscript, with edits from my supervisors (MEJL and DNB). I took the lead in manuscript submission and responding to reviewer comments, with input from my supervisors.

4.1 Overview

This chapter looks at the unique challenges faced when documenting this population, partially answering research question 6:

- What reasons contribute to people with severe obesity not having a BMI recorded?

It highlights the very practical issues encountered in the real-world context by people with larger bodies, and staff caring for them. It illustrates well the need for specific equipment and adjustment of standard methods to accommodate people with larger bodies. Without these adjustments they can be excluded from accurate documentation, which then further excludes them from population planning, covering all facets of life where physical body size may be relevant to services or design including healthcare, transportation, workplaces, clothing, disaster preparedness.

Currently, solutions to the heightened complexity of care due to body size, are largely left to individual staff, rather than having a co-ordinated organisational response (Lumley et al., 2015, Parkinson and Thompson, 2021). In practice this may mean individual staff are left to search for and borrow suitable scales from specialist services such as Weight Management, which is dependent on who they know, rather than the organisation having a clearly articulated policy of provision.

4.2 Abstract

Aims

The number of people with severe obesity (BMI ≥40 kg/m^2) is increasing rapidly, but is poorly documented, partly as a result of inappropriate standard anthropometric measurement methods for community-based people.

Method

As part of a broader study, people receiving care services and with severe obesity were visited at home. The people were assessed for measurements using different weighing scales and standard portable stadiometer. If the stadiometer could not be used, their half arm span and knee height were measured, to estimate their height using standard predictive equations.

Results

Measures were taken for 15 women and 10 men (n=25), aged 40-87 years (mean=62 years). Weights ranged from 98.4 to 211.8 kg (mean=150 kg), with 16 participants requiring bariatric scales. For the six people who were unable to stand, we used wheelchair scales (n=1), bed weighing scales (n=2), routine weights from care home records (n=2) or weight data from hospital records (n=1).

The standard portable stadiometer could only be used for one person; the others required alternative measures from which to estimate height. Large body habitus obscured bony landmarks, meaning alternative measures gave diverse heights. Fourteen participants had ≥8 cm difference in height between estimates from half arm span and knee height measurements.

Conclusions

Standard practice commonly does not provide reliable measurements for people with severe obesity, particularly those with mobility difficulties. An inability to measure weight and height accurately can exclude people from appropriate care, obscuring the true numbers affected and the effectiveness of future service planning. Safe community care requires the availability of specialist

scales, and standardised methods for height estimation appropriate for older and disabled people with severe obesity.

4.3 Background

The public health consequences of severe obesity (body mass index (BMI) ≥40 kg/m^2) on premature mortality and morbidity are well recognised (Khan et al., 2018) and, more recently, the far-reaching impact of stigma on quality of care has received some attention (Phelan et al., 2015). Less well evidenced is that, despite rising numbers of adults globally with BMI ≥40 kg/m^2, documentation of this population is poor (Williamson et al., 2020). Some of this relates to structural issues with health surveys, such as a failure to stratify the group of people with BMI ≥40 kg/m^2 group separately from the BMI ≥30 kg/m^2. However, a detailed reading of the technical reports of such surveys indicates more practical obstacles affecting data collection (NHS Digital, 2020a).

The problems with data collection centre on the suitability of the standard portable equipment used in the community to take anthropometric measures for people with mobility limitations or whose weight is above the equipment's safe working load. Currently, surveys either exclude participants unable to use standard measuring equipment or use self-report estimates (NHS Digital, 2020a). Given that severe obesity is associated with functional limitations including impaired mobility (Backholer et al., 2012), these issues potentially affect the population group with BMI ≥40 kg/m^2 in a disproportionate manner. To date, little attention has been paid to this everyday problem and its potential impact on population studies.

At a population level, failure to properly measure the size and nature of the growing population at the top end of the BMI scale has serious implications. People living with severe obesity – and the staff caring for them - are already struggling with care environments unable to adequately accommodate larger individuals (Lumley et al., 2015, Prasad et al., 2021), resulting in reduced quality of care or feelings of exclusion (Phelan et al., 2015). Other impacts include lack of access to essential equipment, such as computerised tomography scanners, preventing accurate diagnosis and treatment of potentially life-threatening disease (Schapiro, 2021). A failure to collect accurate population measurements today affects the planning and provision of services in the future. This means that care environments and equipment are failing to adapt to key population changes, continuing to exclude rising numbers with severe obesity, and resulting in costly retrospective adaptations or new equipment (Wiles et al., 2017).

The challenges in capturing accurate height and weight measures from people with severe obesity are not limited to health surveys. Similar difficulties are experienced by community practitioners, such as occupational therapists and district nurses, whose role involves ordering home care equipment. An inability to record weight through a lack of suitable scales prevents access to basic care equipment. Most care equipment has a maximum weight threshold, known as a safe working load. As the number of people with severe obesity rises, these maximum weights are increasingly being surpassed, limiting access to routinely used equipment such as hospital beds, rise-recline chairs and hoists (Dockrell and Hurley, 2020). This increases both effort and the risk of harm to individuals with severe obesity and carers alike.

Specialist bariatric care equipment is available, albeit often at increased cost. However, access to, and use of, this equipment is dependent on a current weight to ensure safety and justify increased costs. Valid weight and height measurements are also needed by prescribers to calculate some medication doses (Smit et al., 2018), by dietitians when assessing for weight management or nutritional interventions, and are vital to calculating BMI, in which height errors are squared (Butler et al., 2017).

Access to specialist scales is more likely in hospital settings. A hospital admission or outpatient visit provides an opportunity for an accurate weight recording, but there are time barriers to accessing the necessary equipment (Dockrell and Hurley, 2020). A lack of integration between electronic health record systems mean recordings may not be easily accessed by community or social care staff.

Height measures for people unable to stand, or older adults, are also known to be difficult to achieve accurately, with joint deformation and osteoporosis potential causes of inaccuracy (Butler et al., 2017).

4.3.1 Aims

This study aims to explore the challenges of taking anthropometric measures for people with severe obesity in the community, who have the potential to be excluded from standard approaches.

4.4 Methods

The study was part of broader research into adults with severe obesity in receipt of community health and social care services. Participants were visited at their home or care home, where anthropometric measurements were taken. Participants were aged ≥16 years, and either registered with a GP or living within the local authority area. Recruitment was via health and social care professionals involved in service provision to relevant participants, including the lead author’s (KW) own operational contacts where applicable. This meant that most, but not all, were housebound, pragmatically defined as unable to leave their place of residence without assistance. Professionals provided brief information about the study to potential participants, gaining consent to share their contact details with KW. KW then followed up with full verbal and written information about the study. Those agreeing to participate gave written consent.

The broader mixed-methods research involved a quantitative survey, covering anthropometric measures and service utilisation, and qualitative semi-structured interviews exploring participants’ views on service provision. No weight management intervention was included. Those completing both parts were given a £10 gift voucher in recognition of their time commitment. The South East Scotland Ethics Service deemed the study to be a service evaluation. However, being part of a PhD training, the study received University of Glasgow Ethics approval. The local NHS Board Caldicott Guardian approved all data governance issues. Data collection spanned the first ten months of the SARS-CoV-2 pandemic (mid-February to end December 2020), necessitating a largely operational, pragmatic approach.

4.4.1 Weight measurement

Prior to measures being taken, participants were risk assessed as per Figure 4.1, with outcomes informing equipment selection. If care home residents had a reliable monthly measured weight, this was used to reduce risk of SARS-CoV-2 transmission. The specialist scales used (Figures 4.2-4.4) were not routinely available to community practitioners in the local area, with access negotiated for the study through weight management and manual handling services. Given that the target population of people with BMI ≥40 kg/m^2 has an increased risk of functional disability and falls, due both to body physique and associated comorbidities (e.g. arthritis, stroke and diabetes) (Backholer et al., 2012), portable bariatric stand-on scales (M-530 Marsden, Rotherham, UK) were used for all those able to stand. These are significantly wider, deeper, and lower than standard scales (Figure 4.5) with a higher weight capacity. This enables access for those with wide, heavy legs who may be unable to bring their feet close together, may be unable to see their feet when standing, and may have poor balance. It also prevented stigmatising participants who may feel embarrassed or unsafe if asked to use equipment unsuitable for their size or weight (Phelan et al., 2015). If no suitable scales were identified, alternative sources of weight data were sought.

All these factors promoted safety given the investigator was lone-working in a non-medical environment, typical of working conditions for both community practitioners and health survey interviewers.

The investigator noted participants who could have used standard scales by being:

1. within the weight capacity of standard scales;
2. able to bring feet together;
3. assessed as low risk for falls.

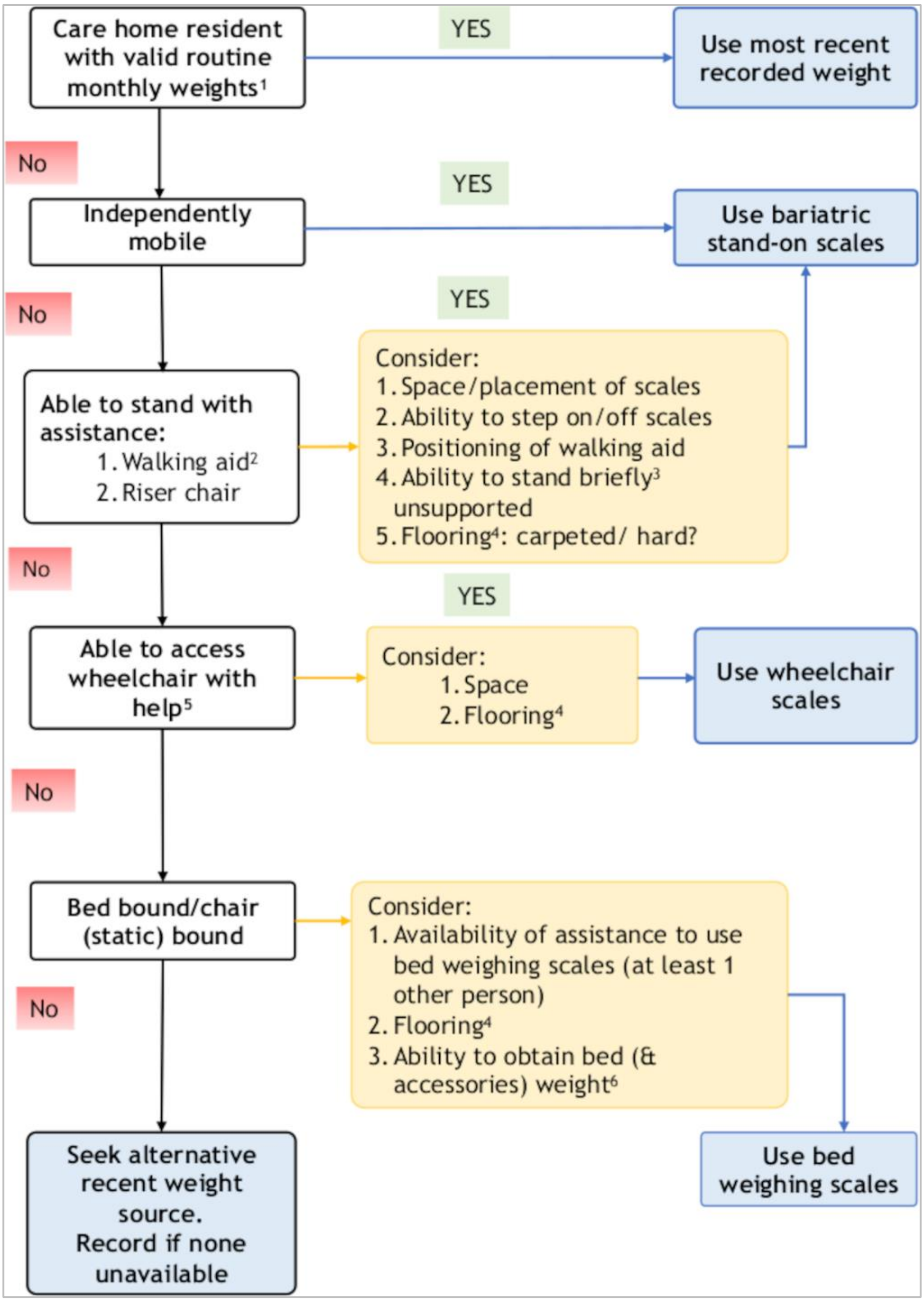

Figure 4.1 Assessment process for determining weighing scales usage.

Legend: [1]measured using calibrated chair or hoist scales; [2]stick/crutch, zimmer frame or wheeled trolley; [3]5-10 seconds; [4]thicker carpet reduces accuracy of measurement whilst increasing manual handling risk; [5]assistance of 1 or 2 informal or formal carers; [6]scales weigh bed plus occupant: need to subtract weight of bed & accessories to obtain individual's weight.

Figure 4.2 Bariatric scales

Legend: width 595 mm, depth 500 mm, height 40mm, capacity 300 kg, (M-530 High-capacity bariatric portable floor scale, Marsden, Rotherham: UK.

Figure 4.3 Wheelchair scales

Legend: 2 portable weighing beams, capacity 300 kg (M-601 portable wheelchair beam scale, Marsden, Rotherham, UK).

Figure 4.4 Bed weighing scales

Legend: (shown with hospital bed), 4 low profile portable pads, capacity 1,000 kg (needs 2+ operators) (M-950 bed weighing scale, Marsden, Rotherham, UK).

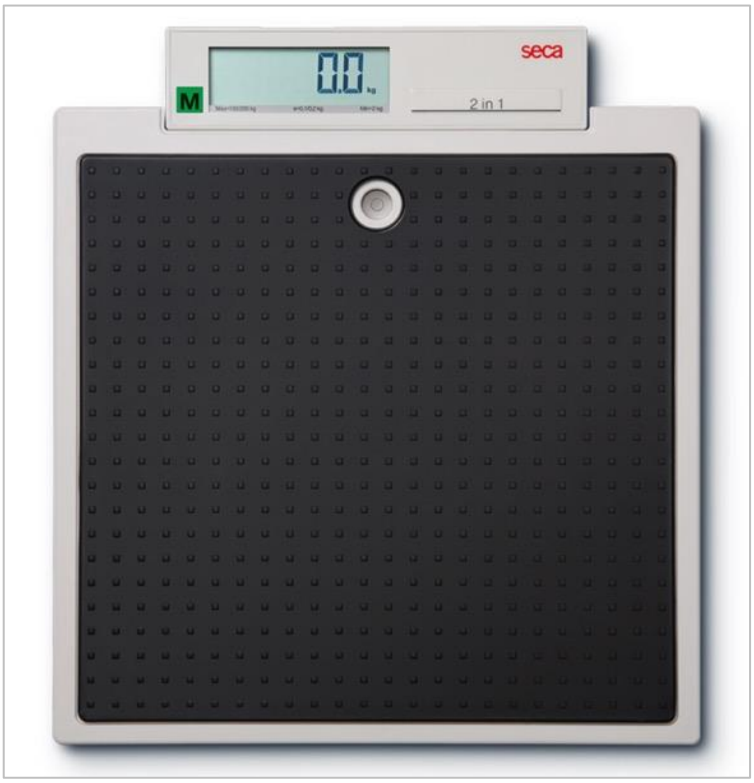

Figure 4.5 Example of standard portable scales

Legend: Width 321mm, height 60 mm, depth 356 mm, capacity 200 kg (Seca model 875, Birmingham, UK).

Figure 4.6 Standard portable stadiometer

Legend: Footplate standing area dimensions: width 320 mm, height 26 mm, depth 335 mm (Seca model 213, Birmingham, UK).

4.4.2 Height measurement

Prior to measurement, participants were risk assessed for their ability to stand safely on a portable stadiometer (Seca model 213, Birmingham, UK) (Figure 4.6), using this if able. For those assessed as unsafe, the Medical Research Council Diet, Anthropometry and Physical Activity toolkit (DAPA) (Medical Research Council, 2019) outlines alternative proxy measures of half arm span (fingertip to sternal notch) and knee height. These were measured with the participant sitting or lying as able, using a steel measuring tape. Height was then estimated as double the half arm span (Hickson and Frost, 2003) and by applying published equations for knee height (Chumlea et al., 1994, Chumlea et al., 1998).

4.5 Results

A total of 15 women and 10 men aged 40-87 years (mean 62 years) participated in the study. Participants were largely recruited through district nursing or occupational therapy staff.

4.5.1 Weight

Weights ranged from 98.4 to 211.8 kg (mean 150 kg). 19 (76%) participants could stand. Of these, three (16%) were assessed as able to use standard scales and 16 (84%) required bariatric scales (largely due to either their leg size, balance or difficulty stepping on or off the narrow raised platform). Six participants were unable to stand and, of these, one used wheelchair scales and two used bed weighing scales. One bed-bound participant was unable to be weighed at home due to a lack of space and carpet in situ and therefore weight data from a hospital admission two months previously was used. Two care home residents (one bed-bound and one chair-bound) had routine monthly weights obtained using hoist or chair scales. Significantly, 80% of participants were housebound, meaning that they were unable to be weighed without specialist scales being brought to them or having a hospital admission. The type of scale used did not appear to be affected by weight (Figure 4.7) or age (Figure 4.8).

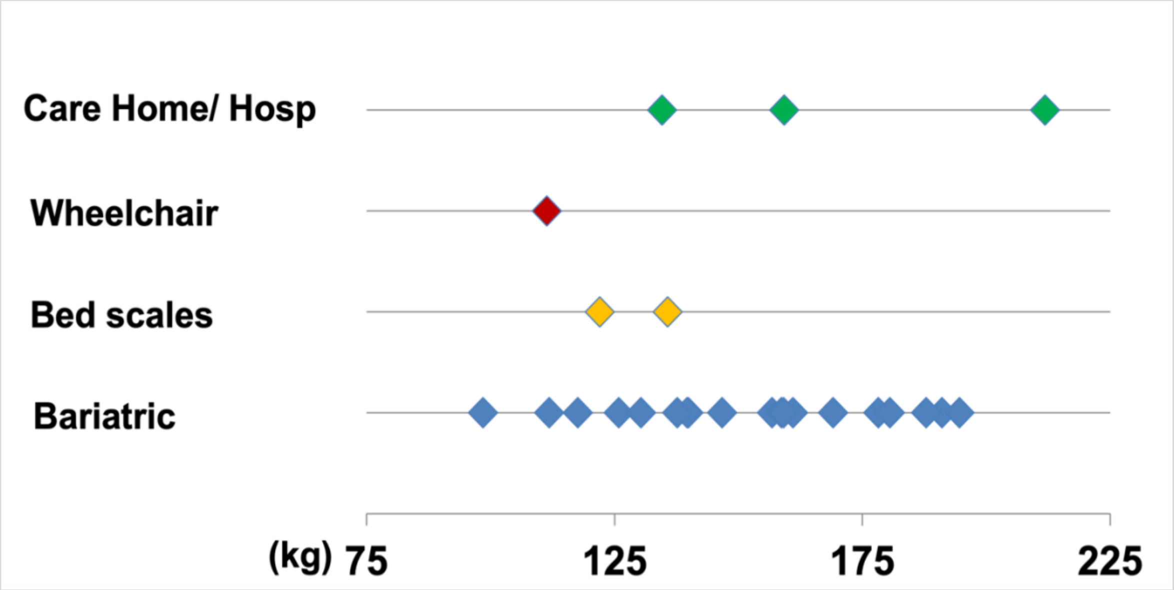

Figure 4.7 Types of scales used by weight (kg)

Legend: Care home/Hosp: weight from a care home or hospital admission used

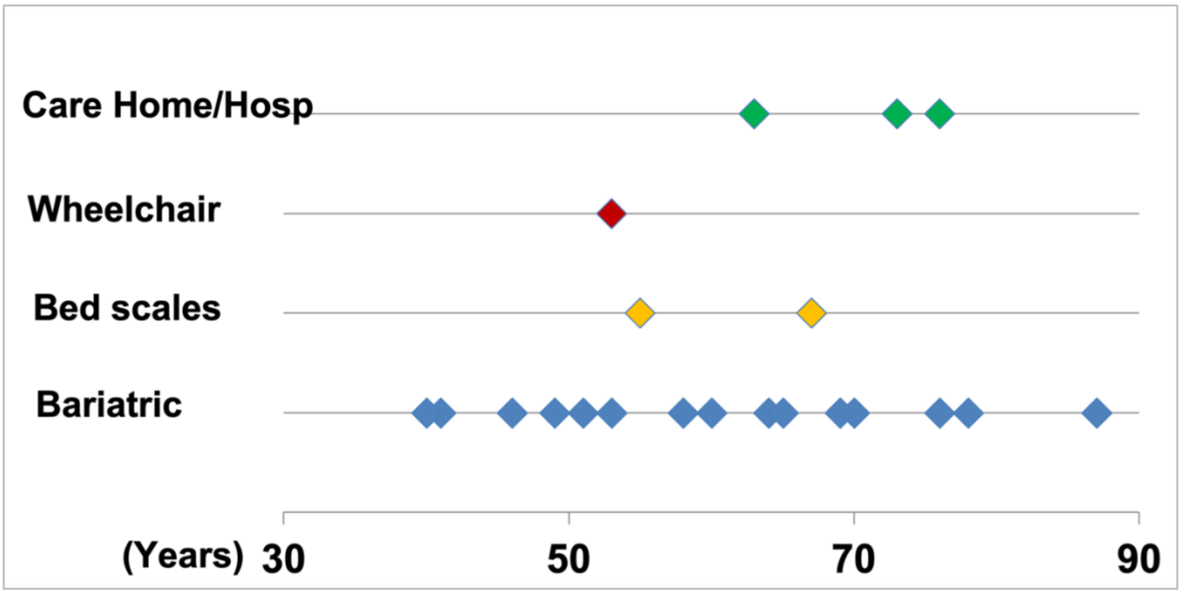

Figure 4.8 Types of scales used by age (years)

Legend: Care home/Hosp: weight from a care home or hospital admission used

4.5.2 Height

The portable stadiometer was difficult to use with this population, and was only used for one participant. The design was a similar narrow footprint to the standard scales, with rounding at the outside edge to further decrease the platform space (Figure 4.6). Participants needed to access it backwards, with the vertical height measure having a degree of movement, while not being able to provide any support. This was judged to be too risky for those with poor balance or mobility impairment. In addition, some participants had body shape characteristics, such as gluteal shelves and kyphosis, which made it difficult to stand upright against the vertical measure.

Physical limitations made alternative height measures of half arm span and knee height difficult to reliably achieve in this population, producing inconsistent results (Table 4.1). To indicate the potential for errors between these methods of measurement and the ultimate classification for a participant, there was a mean difference of 12.3 cm, but with standard deviation (ignoring direction of difference) of 11.3 cm. The sample size was small, but >50% participants had a measurement error ≥8 cm between their knee height and half arm span measures.

A Bland-Altman plot (Figure 4.9) showed no evident funnelling in the distribution of data to indicate bias between the methods. However, the wide difference between the upper & lower levels of agreement (-18.2 to +36.9cm), equivalent to 95% confidence intervals, demonstrates poor reliability within this population.

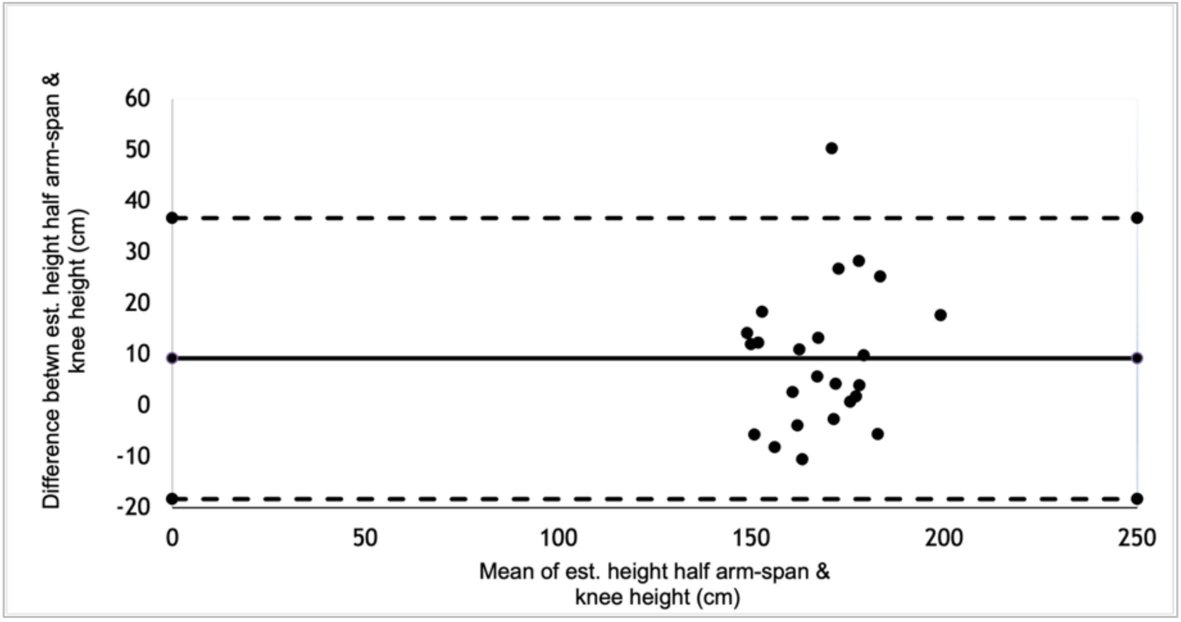

Figure 4.9 Bland-Altman plot comparing estimated height (cm) from half arm span with estimated height from knee height

Table 4.1 Height data comparison by individual

Partici-pant	Age band (yrs)	Sex	Half arm span (cm)	Estimated height: half arm span (cm)	Knee height (cm)	Estimated height[a] knee height (cm)	Discrepancy between estimated half arm span & knee height (cm)	Leg band-aging in situ/ gross oedema
1	40-44	F	81	162	49	159.4	2.6	N
2	40-44	F	87	174	54.5	169.8	4.2	Y
3	45-49	F	87	174	50	160.8	13.2	Y
4	45-49	F	79	158	54	168.5	-10.5	Y
5	50-54	F	81	162	41	143.7	18.3	Y
6	50-54	F	84	168	48	157.0	11	Y
7	50-54	M	88	176	55	175.3	0.7	Y
8	55-59	F	nm	nm	48	156.5	n/a	N
9	55-59	F	78	156	40	141.8	14.2	Y
10	55-59	M	104	208	63	190.3	17.7	Y
11	60-64	M	85	170	53	172.7	-2.7	Y
12	60-64	M	90	180	55	176	4	Y
13	60-64	M	85	170	49	164.3	5.7	Y
14	60-64	M	89	178	55	176.2	1.8	Y
15	65-69	F	98	196	42	145.7	50.3	Y
16	65-69	F	76	152	50	160.2	-8.2	Y
17	65-69	F	80	160	52	163.9	-3.9	Y
18	65-69	F	74	148	46	153.7	-5.7	Y
19	70-74	F	96	192	52	163.7	28.3	Y
20	70-74	M	93	186	47	159.2	26.8	Y
21	70-74	M	92	184	54.5	174.2	9.8	Y
22	75+	F	79	158	43	145.7	12.3	Y
23	75+	F	78	156	42	144.0	12	Y
24	75+	M	90	180	61	185.6	-5.6	N
25	75+	M	98	196	54	170.8	25.2	Y
Mean	62[b]		86.3	172.7	50.3	163.2	12.3	

Legend: nm=not measured (successful measurement using stadiometer, so full range alternative measures not taken); [a]Knee height measure used: if <60 years mobility-impaired formula (Chumlea et al., 1994),if >60 years older adult formula (Chumlea et al., 1998); [b]age is presented as a range to promote anonymity, mean age was calculated from participant's age in rounded years.

4.6 Discussion

This study demonstrates the failure of standard anthropometric measuring equipment to accommodate people with severe obesity due to their larger body size, often further exacerbated by associated disability and comorbidities.

An interesting and unexpected outcome of the study was the difficulty in obtaining valid height measures, even using the alternative measures. Knee height guidance suggests the “angles of the left knee joint and ankle should be 90°” with compression of the soft tissues of the heel and over the head of fibula (Medical Research Council, 2019). To the author’s knowledge, this study is unique in recruiting via district nursing caseloads, with 22 participants having either lower limb ulceration and/or gross oedema, common with severe obesity. For these conditions, the first-line treatment is compression bandaging or hosiery toe-to-knee, shifting the build-up of fluid to around and directly above the knee joint. This directly affected both the ability to achieve a 90°angle and adequate compression of the soft tissues, precluding an accurate knee height measurement. Similarly, joint deformities, contractures and physique impeded sternal notch location and arm raising, which participants found difficult, making half arm span measures inexact.

As the study progressed, pragmatic solutions that were negotiated included taking a participant’s height against a doorpost with a tape measure (doorposts provided support for those with poor balance and were more readily accessible than wall space) (*n*=13) (Gordon et al., 2013). If participants were bed bound, recumbent length measurements (*n*=5) were attempted, but this requires someone else to assist and the participant to lie flat, which may be contraindicated due to weight on the chest compromising breathing. Notably, several of the study participants did not use a bed, instead sleeping in a chair. If these alternative measures were exhausted, self-report was used as a last resort (*n*=6). Current comparisons of self-reported and measured height using large samples show both men and women overestimate height (Flegal et al., 2019). Although the overall mean difference between measures may be small at <1.5 cm, it potentially leads to misclassification by lowering the BMI (Flegal et al., 2019).

Our findings are consistent with research among service providers from hospitals in Ireland (Dockrell and Hurley, 2020) and rural practices in the United States (Agaronnik et al., 2021), highlighting that the lack of provision of scales for those with high weight is itself a barrier to being weighed. Health surveys for both Scotland and England currently use only standard Class III portable scales. Given that functional disability increases with BMI class, this is likely to affect the population with BMI ≥40 kg/m^2 more than other BMI categories, resulting in under-documentation.

Much previous research exploring alternative height measures has limited application to the study group. A large body habitus, along with related comorbidities, frequently prohibits accurate measures of relevant body parts. A previous study by Hickson and Frost (2003) similarly found these measures restricted by a person's functionality and comorbidities in an acutely ill elderly population, a reason why height is often not performed as part of nutritional assessment (Hickson and Frost, 2003). They concluded that there was no ideal surrogate measure, cautioning that within-group comparison should use the same measure. Likely reasons for non-agreement are that older people tend to lose height and measured height may fall with kyphosis or hip and knee arthritis, and arm span reflects maximal adult height rather than true (current) height (Hickson and Frost, 2003). The terms half arm span and demi span are interchangeable from a linguistic perspective (Medical Research Council, 2019), but some papers have used these terms to refer to different measures, using extended finger-tips or finger root, requiring application of the correct calculations (Hickson and Frost, 2003). Other studies are restricted to healthy populations (Butler et al., 2017), actively exclude those with high BMI (Froehlich-Grobe et al., 2011), or consider a disability affecting only one body part, e.g. spinal (Froehlich-Grobe et al., 2011), leaving other viable alternative measures available.

Ulna length, included in the British Association for Parenteral and Enteral Nutrition (BAPEN) Malnutrition Universal Screening Tool (MUST) (BAPEN, 2011) to estimate height for both men and women <65 years and >65 years, was not considered for the present study because it is not included in DAPA's alternative measures (Medical Research Council, 2019). Its focus is undernutrition, so its application to those with BMI ≥40 kg/m^2 is unexplored. Ulna length faces the same issues of locating body landmarks (specifically the midpoint of the styloid process) due to large body habitus, but to a reduced degree, as the forearm suffers less from gross oedema or the joint problems common in lower limbs (Auyeung et al., 2009). Thus, despite evidence suggesting that ulna length is not the most accurate measure in other populations (Butler et al., 2017), ulna length appears to offer greatest potential for accuracy and ease of measurement with this population. This applies even for those with mobility difficulties in community settings, making it an obvious choice for use and further research with this population.

This study provides novel evidence on the challenges of accurate height and weight measurement from a hard-to-reach, largely undocumented population. Although evidence exists in populations with BMI ≥40 kg/m^2, these focus on people receiving weight management treatment (Maston et al., 2019), including bariatric surgery (Gulliford et al., 2017) or hospital-based service utilisation (O'Halloran et al., 2020). There is minimal evidence looking at non-medical or community service utilisation, especially research considering the needs of a housebound population. This reflects difficulties in accessing samples, data collection and the emerging nature of this population.

The participants available and willing to be measured for this study are not a nationally representative sample, but as exemplar cases they offer insights about a population for whom little evidence exists to guide policymakers or care providers. They reflect an important subset of people with BMI ≥40 kg/m^2 most affected by functional disability and therefore with high potential for using health and care services. Standard surveys or secondary research using routine data or population health studies commonly fail to reach this population for reasons already highlighted. Functional disability is seldom wholly attributable to high body weight because other factors, such as arthritis become involved. However, high body weight exacerbates such disability rather than reduces it. Further research disaggregating the wider BMI ≥40 kg/m^2 population into BMI ≥50/60/70 kg/m^2 subsets, or by functional status, might enable improved care provision.

The study evidences the challenges faced by health and social care practitioners when taking anthropometric measures from people with severe obesity in the community. Indeed, there was anecdotal evidence that local practitioners referred people into the study as a means of obtaining their weight due to a lack of local provision. People outside clinical services might assume practitioners have ready access to specialist scales. Paradoxically, it is the very lack of measurement that leads to this population's lack of visibility. What is not measured cannot be evidenced, making it difficult to quantify the need for these scales to managers with constrained resources. This resulting under-documentation is concerning given the use of health survey data to inform future service planning and provision (Williamson et al., 2020). Failure to fully document the population shift of increasing numbers in the right tail of the BMI distribution curve hinders effective modelling of future population projections (Green et al., 2016).

Substantial planning and adaptation are needed to accommodate larger individuals with associated equipment needs, such as tracking hoists, larger rooms to accommodate equipment (Hignett et al., 2007), and more staff to facilitate care (Harris et al., 2018). Implications of these findings are not limited to care services, applying to the design of multiple diverse contexts and environments including transport, crematoriums, housing, and fire and rescue services. Consequently, there is high potential for failure to accommodate affected individuals, without significant and costly retrospective changes to buildings, vehicles, equipment, and staff training. Serious implications for people (Schapiro, 2021, Phelan et al., 2015) and staff (Lumley et al., 2015, Agaronnik et al., 2021) are already evident and likely to worsen.

The need for specialist scales appears to be a gap in the evidence base, particularly affecting, but not limited to, community settings, including health surveys. Procurement of bariatric stand-on scales by non-specialist services is recommended as an initial first step to promoting inclusion, while being relatively cheap and simple to use. Providing access to wheelchair or bed weighing scales is more complex due to increased cost and need for training and risk assessment, but needs to be developed.

4.7 Conclusion

Standard anthropometric methods commonly do not provide reliable measurements for people with severe obesity, particularly those with mobility difficulties. Failure to measure weight and height accurately can exclude people from appropriate care, obscures the true numbers affected, and thus impacts service provision and planning. Safe community care requires the availability of specialist scales, and training in use of standardised methods for height estimation appropriate for use in older, and disabled, people with severe obesity.

Chapter 5 Results: Quantitative data Overlooked and under-evidenced: Community health and long-term care service needs, utilisation, and costs incurred by people with severe obesity

This chapter is published in Clinical Obesity (Open Access).

Williamson, K. Blane, D.N., Grieve, E. & Lean, M.E.J.(2022) Overlooked and under-evidenced: Community health and long-term care service needs, utilisation, and costs incurred by people with severe obesity. Clinical Obesity, e12570, *doi.org/10.1111/cob.12570*

Abstract wording has been amended slightly in this thesis, at the request of PhD examiners, to make the costing estimates easier to understand. Please see Clinical Obesity for version as published.

Contributions: I undertook participant recruitment, data collection, analysis and interpretation, with guidance from my supervisory team. I wrote the initial draft manuscript, with edits from my supervisors (MEJL and DNB). I took the lead in manuscript submission and responding to reviewer comments, with input from my supervisors.

Note about terminology: as outlined in the published paper's introduction, what is termed social care (care homes, formal home care packages of care and day centres) in the UK, is commonly termed long-term care in other health care systems. Hence, adopting that term for a publication in an international journal.

5.1 Overview

This chapter clearly answers research questions 3 and 4:

- What health and social care services does the BMI ≥40 kg/m^2 population use?
- What are the costs of these health and social care services?

As per the secondary objective in Chapter 1, it stratifies the findings into smaller BMI groups, by age, sex, SES and housebound status. It also characterises service provision, answering all the components of research question 7.

- What services are providing care?

    g. Purpose?

    h. Frequency?

    i. Duration?

    j. Episode length?

    k. How many participants are receiving, or have received weight management?

    l. What are the costs of wider health and social care services (Occupational therapy, district nursing, social care, specialist equipment)? Do they vary by BMI group/age/sex?

The paper as published contains relevant detail on methodology. Nevertheless, the word count necessarily limited detailed micro-costing information which was published as Supporting Information and is reproduced in Appendix 2.

Results demonstrate the broad range of costs and length of episodes involved. The evidence is novel and unique, capturing data sources rarely used and presenting robustly verified individual-level data, rooted in real-world service delivery. However, the evidence presented is clearly not definitive in providing a mean per head population-level answer about services used and costs, or how this varies by increasing BMI group, age, sex or SIMD. Nor is it able to separate out the costs associated with obesity from confounding factors, such as age or disability. Thus, the scope for further development of the evidence base is substantial.

High level answers to research objectives regarding equipment and adaptations were given in the published paper, but detailed analysis and discussion were deliberately absent. This was due to limitations of word count, but also because the author believes that they merit a separate paper, given minimal current evidence base. Results have also been excluded from this thesis, with the intention to complete this post thesis submission.

5.2 Abstract

Numbers of people with severe, disabling obesity (BMI$\geq$40 kg/m^2), with need for community health and long-term care (LTC) services, are increasing, but documentation is lacking. We identified individuals with severe obesity known to community health and care professionals in a representative United Kingdom region and used an investigator-administered questionnaire to record needs and use of community health and LTC services. Data were verified against health and LTC records. Local and published sources informed detailed micro-costing. Twenty-five individuals (15 women) consented, aged 40-87 (mean=62) years, BMI 40-77 (mean=55) kg/m^2: 20 participants (80%) were housebound. Twenty-two different cross-sector community health and LTC services were used, including community equipment service (n=23), district nursing (*n*=20), occupational therapy (*n*=14), and LTC (*n*=12). Twenty-four (96%) participants used three or more services, with longest care episode lasting over 14 years. Total annual service costs incurred by participants varied from £2,053 to £82,792 base case estimate, mean £26,594 (lower estimate £2,053 to £80,064, mean £22,462; upper estimate £2,053 to £88,870, mean £30,726), with greatest costs being for LTC. Individual costs for equipment (currently provided) and home adaptations (ever provided) ranged widely, from zero to £35,946. Total mean annual costs increased by ascending BMI category, up to BMI 70 kg/m^2. This study provides a framework with which to inform service provision and economic analysis of weight management interventions. People with severe obesity may need sustained care from multiple community care services.

5.3 Introduction

General population health surveys indicate that the proportion of people with severe obesity (Body Mass Index (BMI) ≥40 kg/m^2) has grown more rapidly than other BMI groups since 1995 (Sturm and Hattori, 2013). Numbers are increasing internationally (Williamson et al., 2020). In England and Scotland adult prevalence rates are 3% and 4% respectively (Scottish Government, 2020a, NHS Digital, 2020b), with a recent estimate predicting English prevalence would more than double by 2035 (Keaver et al., 2018). In the United States (US), adult prevalence has already exceeded 9%, with prevalence for women reaching for 11.7% (Stierman et al., 2021).

Total healthcare costs for people with severe obesity are an estimated 50% higher than those of healthy weight individuals (Kent et al., 2017). However, such estimates are unlikely to be comprehensive. People with severe obesity frequently experience functional limitations and long-term conditions (Backholer et al., 2012, Kyrou et al., 2011), needing skilled input from community-based nursing (Schuldt et al., 2021) and allied health professionals (AHPs) such as podiatrists, physiotherapists, and occupational therapists (OTs). Definitions of total healthcare costs vary globally, but largely focus on medically oriented services (inpatient, ambulatory and medication) (Kent et al., 2017). Just two of the 75 international studies reviewed specifically mentioned nursing, and only one mentioned Allied Health services (Kent et al., 2017).

Consistent with this, growing evidence suggests increasing need for long-term care (LTC) for people with severe obesity. LTC services provide formal (paid), ongoing care for individuals with a functional limitation or activity of daily living (ADL) restriction, usually in a non-hospital setting (Organisation for Economic Cooperation and Development, 2021). When given at home by professional care staff, care is often provided as a formal home care “package of care” (PoC), evolving from more traditional informal (unpaid) provision given by families (Ariaans et al., 2021). Analysis of the English Longitudinal Study of Aging (adults ≥65 years) found people with severe obesity had double the need for formal home care at nearly double the cost, compared with an individual of BMI 23 kg/m^2 (Copley et al., 2017). Additionally, people with BMI ≥45 kg/m^2 were nearly six times more likely to use formal home care than those with BMI 18.5-

24.9 kg/m^2 (Gousia et al., 2019). For people needing residential care, US nursing homes show a steady rise in admissions for those with severe obesity (Zhang et al., 2019a), with staff from care homes in England and New Zealand reporting similar trends (Hales et al., 2020a, Parkinson and Thompson, 2021).

LTC systems vary widely by country, with differences around terminology, funding, and accessibility, making discussion at international level complex (Ariaans et al., 2021, Organisation for Economic Cooperation and Development, 2021). However, many LTC systems are experiencing common drivers for change: burgeoning numbers of older people and individuals with non-communicable diseases (Ariaans et al., 2021), including obesity (Local Government Association, 2020). These drivers impact the sustainability of current systems, prompting evolution (Feeley, 2021). Yet access to robust LTC data can be difficult (Organisation for Economic Cooperation and Development, 2021), meaning relevant services are themselves orphan areas of research, hampering effective future service planning (Nicholas et al., 2020).

The context for this study is Scotland, United Kingdom (UK) where the publicly funded National Health Service (NHS) is largely free at point of care, based on clinical need. In contrast, LTC services (termed social care in the UK) comprising residential care, home care, and day-care services (Bottery and Jefferies, 2022, Feeley, 2021), have historically been funded by a mix of public & private (largely individual) funding (Atkins et al., 2021). In 2018/19, formal adult social care expenditure for Scotland was £3.8 billion, with 84% funding from the public sector (Feeley, 2021). Public sector costs for England reached £26 billion in 2020/1 (Bottery and Jefferies, 2022). Given these costs, better understanding of service utilisation is essential. Responsibility for provision lies with local authorities, who commonly apply thresholds relating to functional status and age (≥65 years), with varying degrees of means testing (Atkins et al., 2021). Devolved government means some differences between the four UK nations, such as free personal and nursing care for adults ≥65 years in Scotland (Atkins et al., 2021). However, in all four countries, adults who meet the relevant needs and means tests are eligible for state-funded care (Atkins et al., 2021).

This study was precipitated by the lead investigator’s clinical observations as a district nurse, on care provided by community health and LTC services to people with severe obesity. They found a lack of evidence to support service development and inform person-centred care, particularly for people who are housebound (Pokorny et al., 2009, Holt and Hughes, 2020). This gap prevents fully comprehensive economic costings of obesity's impact, leading to potential underestimation of the benefits of weight management interventions (Grieve et al., 2013). This then impedes informed decision making regarding interventions and policies (Grieve et al., 2013, Gousia et al., 2019), and hampers service development (Schuldt et al., 2021). The aim of this study was to document individual-level community health and LTC service usage for an exemplar cohort of people with severe obesity. In illustrating the need for, and range of, services used, and costs involved, it highlights a new area for research, signposting hitherto neglected data sources.

5.4 Methods

5.4.1 Setting

A Scottish local authority area, broadly representative of the Scottish general population by age and long-term health conditions (National Records of Scotland, 2021a).

5.4.2 Participant selection

People with severe obesity are often considered a "hard-to-reach" population, so purposive sampling was used, with potential participants recruited via community professionals (Figure 5.1) between February-December 2020. Eligibility criteria were, adults aged 16 years and over, in receipt of care services, able to provide informed consent, and identified as likely to have a BMI ≥ 40 kg/m^2. Due to the undocumented nature of the study population, participant numbers were unclear at the study's outset. Sample size was dictated by balancing study resources with the aim of robustly evidencing exemplar cases and achieving data saturation of the type and scale of services used.

Potential participants were excluded if community professionals deemed them unsuitable due to potential for distress, or safety concerns in their home environment. To indicate the wider number of people with severe obesity using services, community health services and local authority run LTC services were asked to conduct a retrospective caseload "census" for eligible people. Basic demographic details were collected for these individuals.

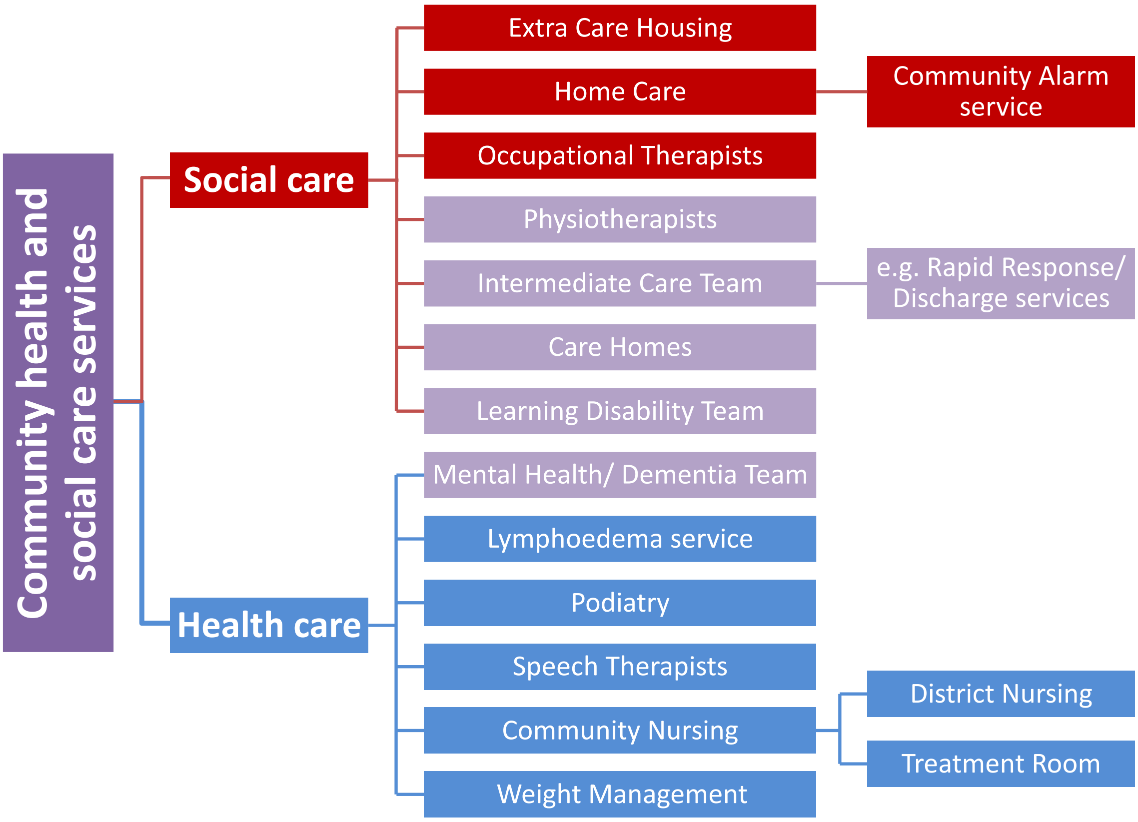

Figure 5.1 Services approached for recruitment of participants

Legend: Services in red primarily local authority provided long-term care services; services in blue primarily health provided services; services in purple more mixed/jointly-provided services.

5.4.3 Study design and data collected

Participants were visited at home by the lead investigator, who obtained written informed consent for participation. Participants' height and weight were measured using specialist scales and alternative height measures if required (Williamson et al., 2022b). The investigator then administered a "Help at Home" questionnaire (Appendix 2), gathering information on help needed at home. This was based on methods used by Health Survey England to assess formal and informal help needed with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (NHS Digital, 2018b, Copley et al., 2017). Self-reported use of community health, OT, and social work (SW) covered the preceding 12 months; LTC services (care home and home care PoC) covered the preceding month. Data also included medical equipment and housing adaptations.

Participants' health and LTC records were used to verify self-reported data. Unlike hospital episodes which are typically measured in days, community episodes which frequently involve providing supportive care for long-term conditions, can last months, sometimes years. Due to the potential for poor recall (such as length of care episode), participants agreed that any discrepancies would be resolved by using recorded data.

Participants provided data on both informal (non-paid) care and private paid domestic help, e.g., help with housework or shopping. However, these data were excluded from the present analyses. Data were not collected about any private contributions to participants' care costs, due to the very high degree of comprehensive publicly funded care in Scotland and the difficulty of collecting such potentially intrusive data. Given limited study resources the focus was on largely unevidenced LTC, nursing, and AHP data sources. General practitioner (GP) services were excluded from detailed data collection partly due to added data governance complexity, and the existence of a more developed evidence base (Kent et al., 2017).

Data collection coincidentally occurred during the Covid-19 pandemic, necessitating a largely operational approach. This meant minimising face to face contact, wherever possible undertaking data collection alongside essential care provision, and using NHS-approved Covid-19 mitigation measures, such as personal protective equipment. A subset of participants undertook a semi-structured qualitative interview regarding their experience of services (to be reported elsewhere), with participants who completed both the questionnaire and interview receiving a £10 shopping voucher in appreciation of their time.

5.4.4 Data analysis

Electronic community health records clearly documented duration and frequency of visits for health staff by service. Home care PoC schedules were routinely summarised in local authority electronic records when starting or changing provision, providing robust timings. Thus, verified dose of care was calculated for each participant using frequency of contact by duration of contact giving a monthly dose of care (hours) by service (further detail is provided in Appendix 2).

Verifying estimated duration of contact for local authority employed community OT and SW roles was more complex. This was because local authority electronic care records were largely narrative, with no indication of staff time input. It also reflects that other than for intermediate care staff, such as Rapid Response teams, much input is indirect, e.g., sourcing equipment, rather than direct care provision with individuals (Curtis and Beecham, 2018). Little guiding literature exists around estimation of staff time in such roles (Curtis and Beecham, 2018). Common practice in such situations is to consult with experienced professionals for guidance (NHS National Services Scotland, 2019).

Discussion with local OT Team leads produced three broad time bands of low (<5; median 2.5 h), medium (5-9.9; median 7.5 h), and high (10-15; median 12.5 h) hours per week input. The same team leads used their knowledge of the caseload work for participants to allocate participants to low-medium (referred to hereafter as “low”) or medium-high (referred to hereafter as “high”) time bands, allowing a directed sensitivity analysis. A mean staff time estimate was calculated of 5 h for low time band participants and 10 h for high time band participants. These time estimates were then used to calculate the most likely estimated OT costs, used as the base case. For the small number of participants (*n*=5) with SW input, no local or published guidance was available. Low time band estimates were therefore applied, to keep costs conservative. OT/SW roles involved largely indirect input in support of both LTC and community health services, therefore, are presented as distinct OT/SW outcomes for clarity.

Local and published sources (Curtis and Beecham, 2018, Curtis and Burns, 2020) applying 2019/2020 values, informed a micro-costing of participants’ monthly dose of care by service, multiplied by 12 for annual costs. Annual costs for community health, LTC, and OT/SW sectors were combined to give a total annual cost for publicly funded services used by each participant and to calculate mean cost per participant across the sample. Equipment (currently provided) costs and adaptations costs (ever provided) were calculated separately to give a total figure, as these were typically one-off, longer term costs (Curtis and Beecham, 2018). Detailed micro-costing methodology is in Appendix 2.

The costs presented in Results are the base case cost estimates using the mean OT/SW time estimates outlined above. Sensitivity analysis was also undertaken using the lower- and upper-time estimates for OT/SWs (see Table 2 in Appendix 2 for summary figures), with costs presented accordingly.

Care home costs greatly exceeded maximum home care costs, producing notably different values for the small number of participants in care homes. Therefore, a second sensitivity analysis was undertaken, replacing care home costs with either mean (based on home care users only) or maximum home care costs. Maximum home care is arguably more applicable, as admission to care home frequently occurs when care needs exceed that deliverable as a home care PoC. Mean cost quoted in Results is the base case OT/SW costs and original care home costs, unless otherwise stated.

Planned outcomes were descriptive statistics regarding BMI, help received from formal services, type and quantity of help used, and publicly funded cost of services used. Mean costs were stratified by BMI group (40-49, 50-59, 60-69, 70+ kg/m^2), age, sex, and Scottish Index of Multiple Deprivation (SIMD) decile (grouped into deciles 1-5 and 6-10, with 1 being most deprived) (Scottish Government, 2020b), for comparison. Analysis was conducted for all participants and a subgroup consisting of LTC users only. Comparative analysis focused on services providing the most intense dose of care to the greatest number of participants.

5.4.5 Ethical considerations

NHS Research and Development and South East Scotland Ethics service deemed the project service evaluation, with approval from the University of Glasgow Medical, Veterinary and Life Sciences Ethics Committee (Project Number 200180200) (Appendix 4) as a doctoral study. The local Caldicott Guardian oversaw data governance approvals.

5.5 Results

Results are presented in the following categories: Demographics, service utilisation, help provided, and costs.

5.5.1 Demographics

There were 25 participants and 32 non-participants. Reasons for non-participation reflected the exclusion criteria and are detailed in Table 5.1. Participants were 15 women and 10 men (*n*=25), aged 40-87 years (mean=62 years), BMI 40-77 (mean=55) kg/m^2, 20 (80%) were housebound, and seven (28%) lived alone. Participants reflected obesity's association with lower socio-economic status, with 17 (68%) from SIMD deciles 1-5. Key demographics are summarised in Table 5.2.

Table 5.1 Reasons for non-participation

Reasons for non-participation from wider services	Number
Unable to contact	1
Incapacity	2
Unwell	3
Staff safety concerns[1]	3
Declined[2]	4
Census[3,4]	19

Legend: [1]Standard practice for two staff to attend to ensure safety; not possible as part of study, [2]Varying reasons given: covid transmission risk (*n*=1), time burden (*n*=1), not wanting to be audio-recorded during interview (*n*=1), did not want data to leave NHS (*n*=1), [3]identified as eligible by community professionals, who advised investigator that individuals were unsuitable to approach for participation, due to sensitivity of home circumstances (e.g. mental/physical distress, carer stress), [4]participants identified towards end of recruitment period when study capacity already reached.

Table 5.2 Participants' demographics summary by BMI (kg/m^2) group

	ALL	BMI 40-49	BMI 50-59	BMI 60-69	BMI 70+
Number	25	8	9	5	3
Women % *(n)*	60 *(15)*	63 *(5)*	44 *(4)*	80 *(4)*	67 *(2)*
Range BMI (kg/m^2)	40-77	40-49	50-57	61-67	70-77
Mean BMI (kg/m^2)	55	44	53	64	74
Range Age (years)	40-87	41-78	40-87	51-76	46-65
Mean Age (years)	62	60	67	61	57
Under 65 years % *(n)*	56 *(14)*	50 *(4)*	44 *(4)*	80 *(4)*	67 *(2)*
Lives alone % *(n)*	24 *(6)*	50 *(4)*	22 *(2)*	0	0
Housebound % *(n)*	80 *(20)*	75 *(6)*	89 *(8)*	60 *(3)*	100 *(3)*
SIMD[1] 1-5 % *(n)*	68 *(17)*	75 *(6)*	44 *(4)*	80 *(4)*	100 *(3)*

Legend: [1]Scottish Index of Multiple Deprivation (1=most deprived).

5.5.2 Service utilisation

As a group, participants were using 22 different community health and LTC services (Table 5.3), ranging between 1-12 services by participant (mean 7, median 7) (Figure 5.2). Twenty-four (96%) participants received three or more services, with 17 (68%) receiving six or more services.

LTC use ranged from 1 to 132 (mean 22) months, four (16%) participants were >5 years, with service still ongoing. OT/SW input was generally episodic (mean 8 months), finishing once equipment, or adaptation, or PoC was provided. However, input varied, including one individual with very long-term input at 62 months, with service still ongoing. District nursing recorded the longest episode at 174 (mean 38) months, with 12 (48%) participants receiving district nursing care for ≥2 years, and five (20%) participants for ≥5 years. Analysis by ascending BMI group found increasing mean length of episode for DN services alone (Figure 5.3).

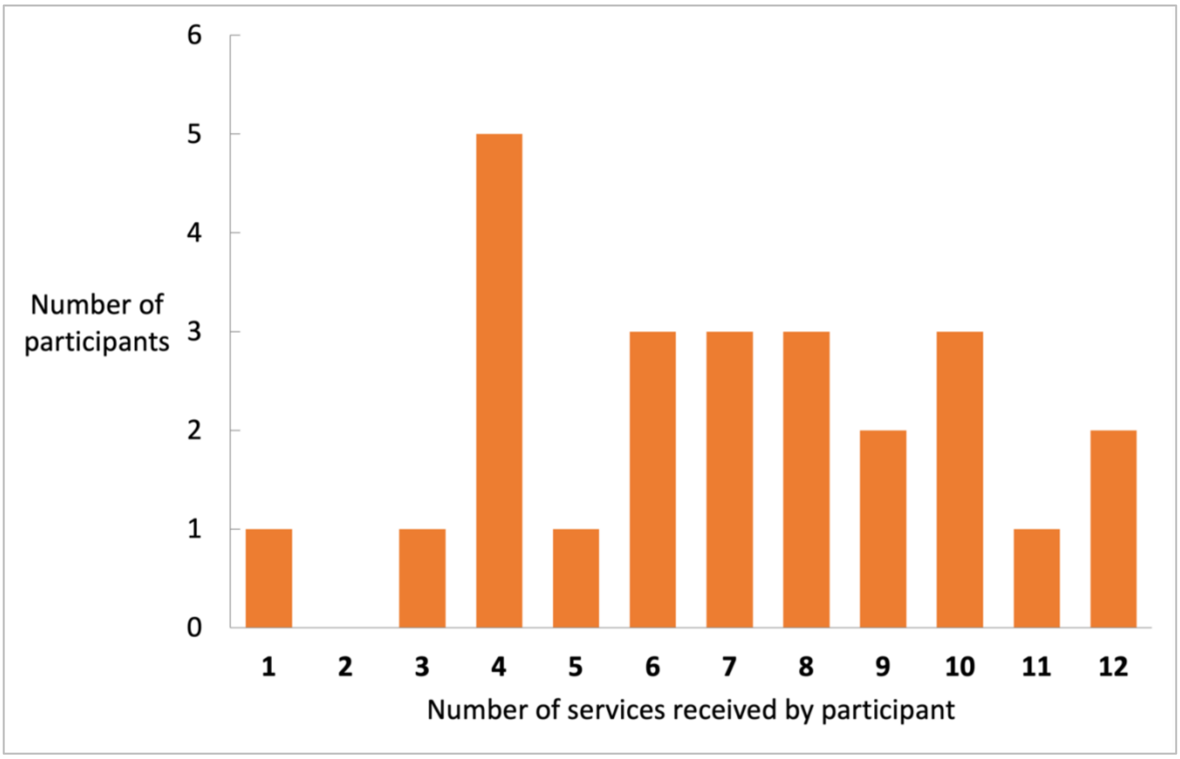

Figure 5.2 Service utilisation by total number of services used by participants

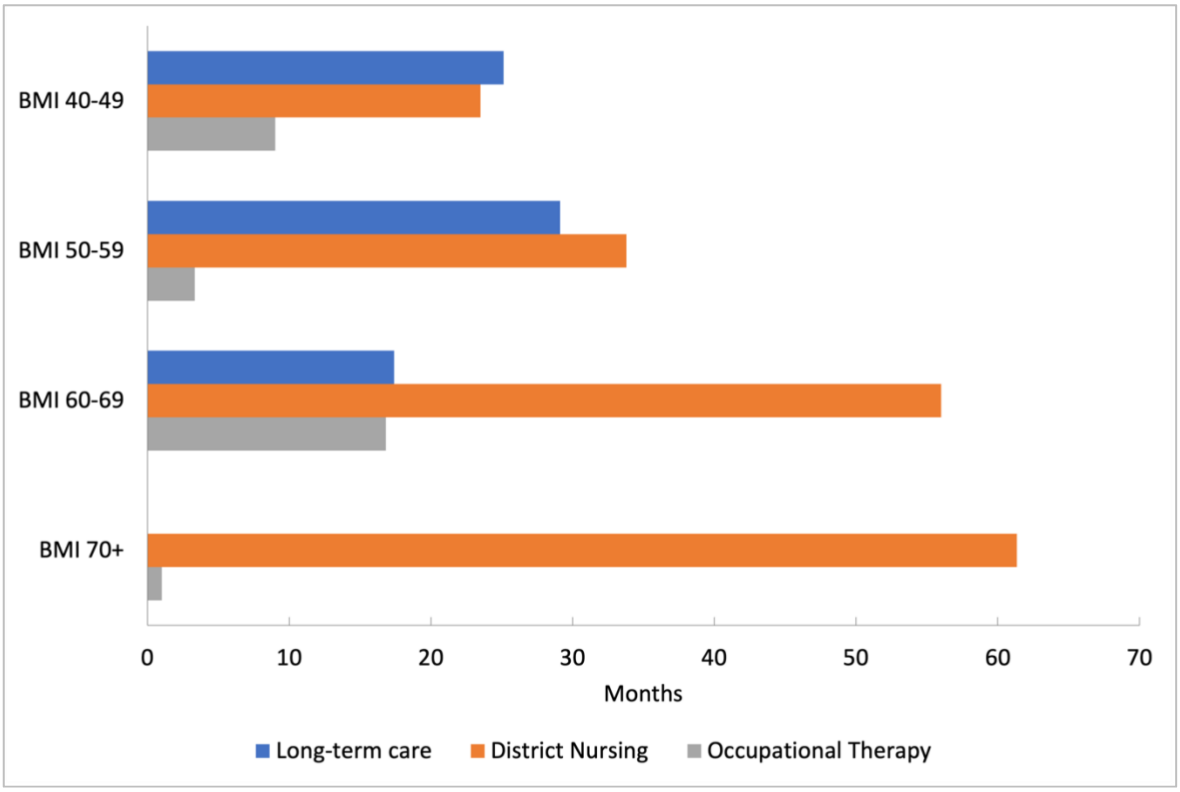

Figure 5.3 Mean length of episode (months) by service/BMI (kg/m^2) group

Table 5.3 Service utilisation of community and long-term care services by participants

Nursing Services	Mobility/ Function	Local Authority/ Long-term care	Support services	Allied Health Professionals	Medical/ Medication
District nurse (20,*2*)	Community equipment store (23)	Community occupational therapist (14,*10*)	Wheelchair centre (13)	Podiatry (9,*3*)	Community pharmacy delivery service (18)
Tissue viability nurse (4,*1*)	Community physiotherapist (including Rapid response/ Community rehab team) (8,*10*)[2]	Local authority funded home care (10,*1*)	Continence service (7)	Weight management (dietitian, psychologist) (5[3],*8*)	
Bowel & bladder specialist nurse (1, 2)	Community alarm service (including Key safe/ Falls/ OOH toileting support) (14)	Social work (including housing support/ welfare rights Team) (9,*5*)	Orthotics (*6*)	Lymphoedema service (10,2)	
Marie Curie services[4] (1)		Care home (2,*1*)	Citizen’s advice bureau (1)	Mental health team (CPN/ Psychiatrist) (5,*5*)	
		Day centre (1)	Fire service (assess housing) (1)		
		Bin “pull out” service (1)	Third sector carer support (*1*)		

Legend: (Numbers in brackets=participants currently receiving service or an ongoing support service, *italics=further participants who had received service in past*), (Black=Health and Social Care Partnership (HSCP)[1]; blue=wider NHS service; grey=Third sector; yellow=other statutory services); [1]including independent providers (pharmacies, home care agencies) contracted to provide services to HSCP; [2]including community rehabilitation team/rapid response team/intermediate care (service/team configurations were dynamic during Covid-19 response period); [3]two had received treatment in the past year, three were on the waiting list; [4]specialist nursing care providing end of life support at home.

5.5.3 Help provided

Local authority-employed care professionals (OT/SW) provided input for housing and adaptations, equipment, welfare support (benefits and grants), and adult support and protection concerns. They also arranged LTC provision, including respite care. Dose of care ranged from a 1 h per month (intermediate care OT input) up to 10 h per week (as detailed earlier in Section 5.4.4).

Community health services focused on enabling participants to live safely at home by promoting functional status, helping to manage long-term conditions, and direct provision of supportive care (individual service examples are available in Appendix 2). Dose of care ranged from a 0.5 h annual review visit by lymphoedema services up to 5.5 h per week input from district nurses (wound care and twice daily insulin administration).

LTC provision included assistance with ADLs due to functional limitations, notably personal care (washing/dressing/toileting/skincare), mobility, medication, and meal preparation. Two (8%) participants permanently resided in care homes. Home care dose of care ranged from 3.5 h weekly (0.5h once daily by one carer) up to 36.6 h weekly (2 h daily, plus 4.3 h weekly unplanned out of hours care, all by two carers). Five (20%) participants needed two carers due to moving and handling requirements. Four (16%) participants received the maximum of four planned visits daily, with two (8%) of these participants regularly (weekly or more) having extra, unplanned out of hours care for falls/toileting.

Twelve (48%) participants received LTC provision via local authority services, with a further one (4%) having specialist toileting equipment provided to prevent home care input and another one having had temporary LTC in the past, when their informal carer was unavailable. Participants using LTC were generally older than those with no LTC (mean 70 and 55 years respectively), although three (12%) participants receiving LTC were <65 years. Men were >7 years older than women in both groups. Five (20%) participants in the LTC group lived alone, compared with two (8%) in the group with no LTC.

Twenty-four (96%) participants received input from informal carers, ranging from the same as that provided by LTC services to sporadic help with gardening, paying bills, or assistance cutting nails. The range of help provided by informal carers was much broader than that included by home care services indicating the restriction of home care services to essential care, with informal care "wrapping round" to fill the gaps, including shopping, housework, and paying bills.

Five (20%) participants had contact with weight management services. Two (8%) participants were receiving treatment, with another three (12%) on the waiting list, meaning the sample was principally non-treatment seeking. A further eight (32%) indicated engagement with weight management services in the past (Table 5.3).

5.5.4 Costs

Total annual costs for community health, LTC and OT/SW service varied from £2,053 to £82,792, mean £26,594 (Table 5.4). Figure 5.4 plots individual participant totals broken down by sector, demonstrating the wide range: Nine (36%) participants had costs <£10,000, ten (40%) participants had costs between £10,000-£49,999, whilst six (24%) participants had costs >£50,000.

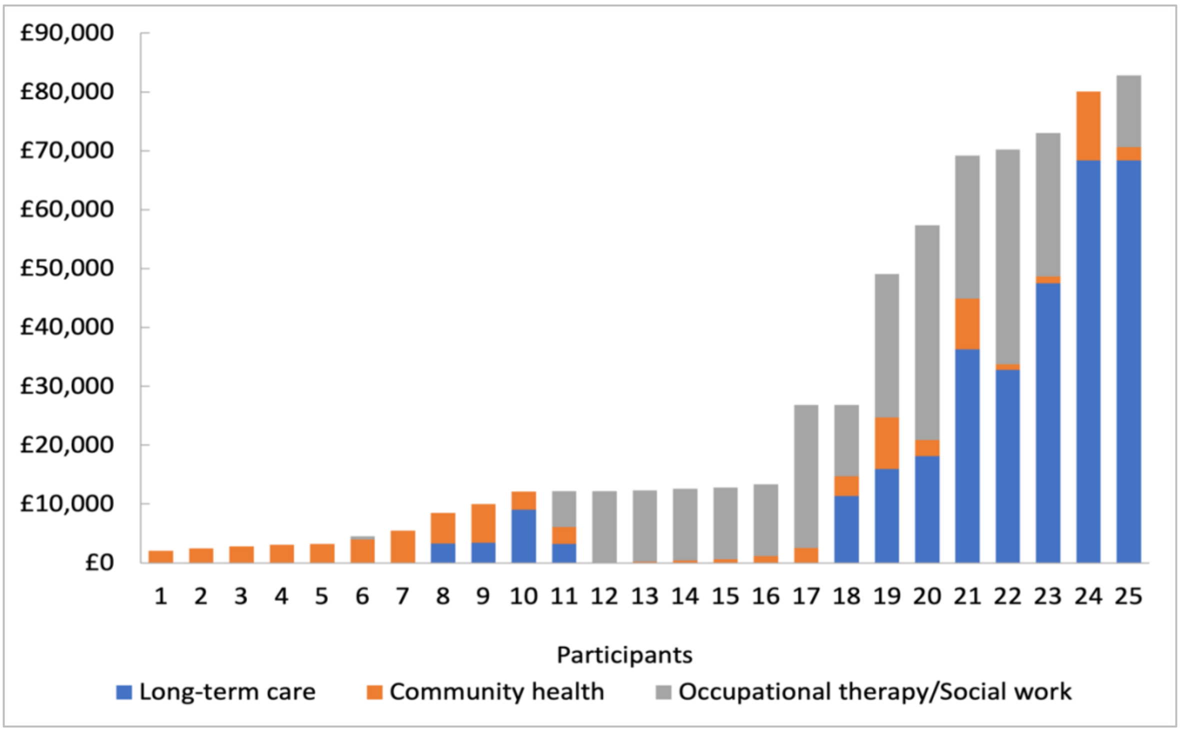

Figure 5.4 Total annual care costs (£) by participant by sector

Table 5.4 Individual-level service utilisation and costs by participant

Sex	BMI	Age	SIMD[1]	Long-term care costs[2]	Health care costs	OT/ SW costs lower	OT/ SW[3] costs base case	OT/SW costs upper	Annual Care costs lower	Annual Care costs base case	Annual Care costs upper	Equip-ment	Adapt-ations	Total Equip-ment/ Adapt-ations	Length of episode (months)		
															LTC	DN	OT
M	40-44	50-54	1-5	£0	£2,053	£0	£0	£0	£2,053	£2,053	£2,053	£866	£6,401	£7,267	0	17	0
F	40-44	65-69	1-5	£11,340	£3,372	£6,072	£12,150	£18,228	£20,784	£26,862	£32,940	£2,031	£5,354	£7,385	6	2	5
M	40-44	70+	1-5	£3,213	£2,874	£6,072	£6,072	£6,072	£12,159	£12,159	£12,159	£2,299	£120	£2,419	28	38	0
M	40-44	70+	1-5	£15,984	£8,757	£12,144	£24,300	£36,456	£36,885	£49,041	£61,197	£5,903	£85	£5,988	36	24	3
F	45-49	40-44	1-5	£0	£636	£6,072	£12,150	£18,228	£6,708	£12,786	£18,864	£296	£6	£303	0	0	1
F	45-49	45-49	1-5	£0	£3,978	£540	£540	£540	£4,518	£4,518	£4,518	£389	£177	£566	0	2	1
F	45-49	50-54	6-10	£18,144	£2,730	£24,300	£36,450	£48,600	£45,174	£57,324	£69,474	£6,143	£7,948	£14,091	122	83	62
F	45-49	65-69	6-10	£3,321	£5,148	£0	£0	£0	£8,469	£8,469	£8,469	£115	£85	£200	9	22	0
F	50-54	40-49	1-5	£0	£190	£6,072	£12,150	£18,228	£6,262	£12,340	£18,418	£0	£6,517	£6,517	0	0	3
M	50-54	60-64	6-10	£0	£2,525	£12,144	£24,300	£36,456	£14,669	£26,825	£38,981	£4,237	£405	£4,642	0	36	4
M	50-54	60-64	6-10	£0	£5,460	£0	£0	£0	£5,460	£5,460	£5,460	£2,320	£412	£2,732	0	3	0
F	50-54	65-69	6-10	£32,805	£960	£24,300	£36,450	£48,600	£58,065	£70,215	£82,365	£25,495	£10,451	£35,946	132	38	8
M	50-54	70+	1-5	£68,364	£11,700	£0	£0	£0	£80,064	£80,064	£80,064	£8,174	£0	£8,174	21	21	0
M	50-54	70+	1-5	£9,017	£3,090	£0	£0	£0	£12,107	£12,107	£12,107	£597	£269	£866	108	174	0
M	55-59	55-59	6-10	£0	£2,808	£0	£0	£0	£2,808	£2,808	£2,808	£2,367	£160	£2,527	0	29	0
F	55-59	70+	6-10	£0	£2,457	£0	£0	£0	£2,457	£2,457	£2,457	£0	£0	£0	0	2	0
F	55-59	70+	1-5	£68,364	£2,278	£6,072	£12,150	£18,228	£76,714	£82,792	£88,870	£7,458	£0	£7,458	1	1	15
F	60-64	55-59	1-5	£47,520	£1,170	£18,228	£24,300	£30,372	£66,918	£72,990	£79,062	£12,754	£18,626	£31,380	64	159	20
M	60-64	60-64	1-5	£36,288	£8,589	£18,228	£24,300	£30,372	£63,105	£69,177	£75,249	£9,524	£15,786	£25,310	2	69	40
F	65-69	50-54	1-5	£0	£432	£6,072	£12,150	£18,228	£6,504	£12,582	£18,660	£3,685	£30,576	£34,261	0	0	18

Sex	BMI	Age	SIMD[1]	Long-term care costs[2]	Health care costs	OT/ SW costs lower	OT/ SW[3] costs base case	OT/SW costs upper	Annual Care costs lower	Annual Care costs base case	Annual Care costs upper	Equip-ment	Adapt-ations	Total Equip-ment/ Adapt-ations	Length of episode (months)		
															LTC	DN	OT
F	65-69	55-59	1-5	£0	£1,176	£6,072	£12,150	£18,228	£7,248	£13,326	£19,404	£6,163	£11,052	£17,215	0	0	6
F	65-69	70+	6-10	£3,443	£6,530	£0	£0	£0	£9,973	£9,973	£9,973	£5,436	£148	£5,584	21	52	0
F	70+	45-49	1-5	£0	£3,215	£0	£0	£0	£3,215	£3,215	£3,215	£420	£6,226	£6,646	0	145	0
M	70+	60-64	1-5	£0	£3,096	£0	£0	£0	£3,096	£3,096	£3,096	£5,908	£6,576	£12,484	0	39	0
F	70+	65-69	1-5	£0	£72	£6,072	£12,150	£18,228	£6,144	£12,222	£18,300	£2,056	£6,814	£8,870	0	0	3
Mean All	55	62		£12,712	£3,412	£6,338	£10,470	£14,603	£22,462	£26,594	£30,726	£4,585	£5,368	£9,953	22	38	8
Mean LTC users	51	70		£26,484[4]	£3,412	£10,564	£17,451	£24,338	£40,459	£47,346	£54,233	£4,984	£6,100	£10,368	46	48	14

Legend: [1]Scottish Index of Multiple Deprivation (1=most deprived); [2]care home or home care package of care (local authority provision); [3]Community occupational therapist/social worker base case costs; [4]mean for home care service users only £18,107.

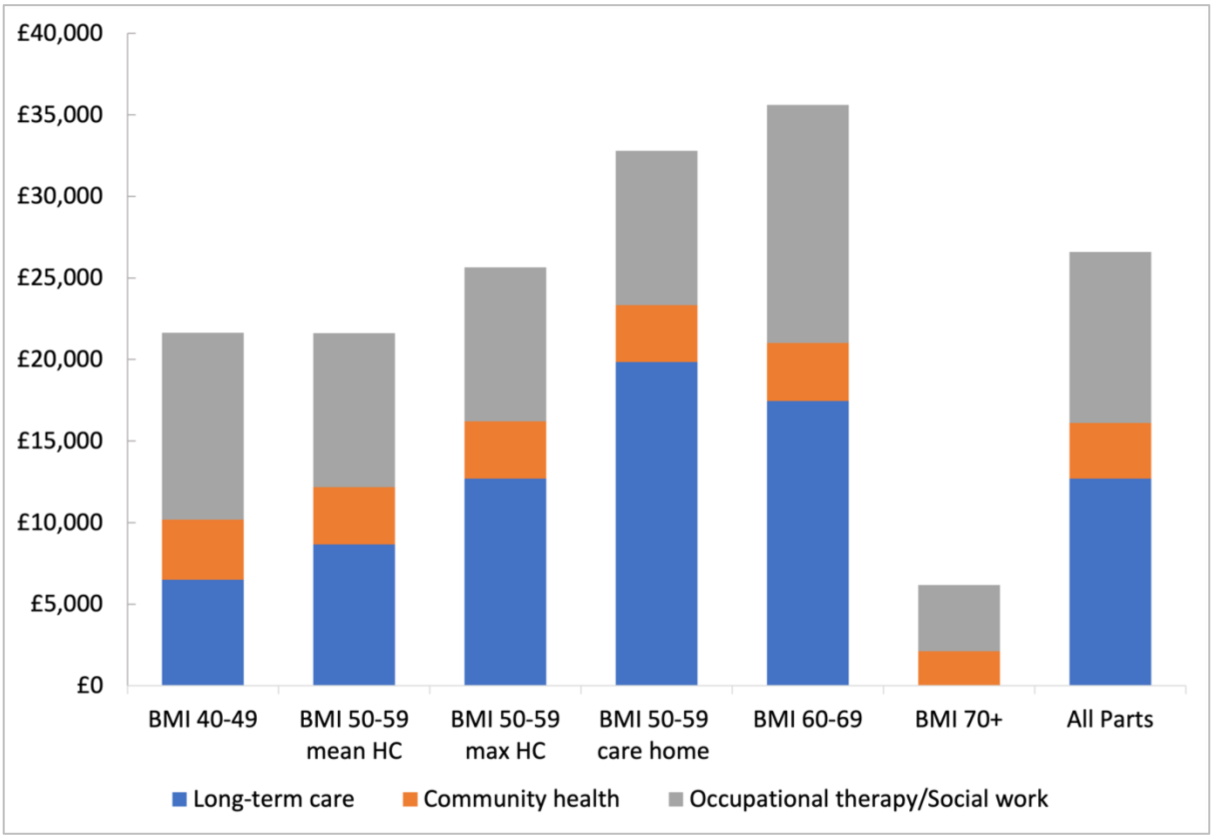

Figure 5.5 Mean annual care costs (£) by BMI group (kg/m^2) by sector

Legend: All participants (All Parts), including sensitivity analysis for BMI 50-59 group by mean home care (mean HC) costs, maximum home care (max HC) costs and original care home costs.

Costs by sector (Figure 5.5) were highest for LTC services (£3,213-£68,364; mean £12,712), followed by OT/SW costs (£540 to £36,450; mean £10,470), with lowest costs for community health services (£72-£11,700; mean £3,412). Sensitivity analysis applying lower- and upper-time bands for OT/SW staffing costs gave upper estimate total costs £88,870 (mean £30,726) (Figure 5.6), whilst the lower estimate total costs were £80,064 (mean £22,462) (Figure 5.7) (Table 5.4).

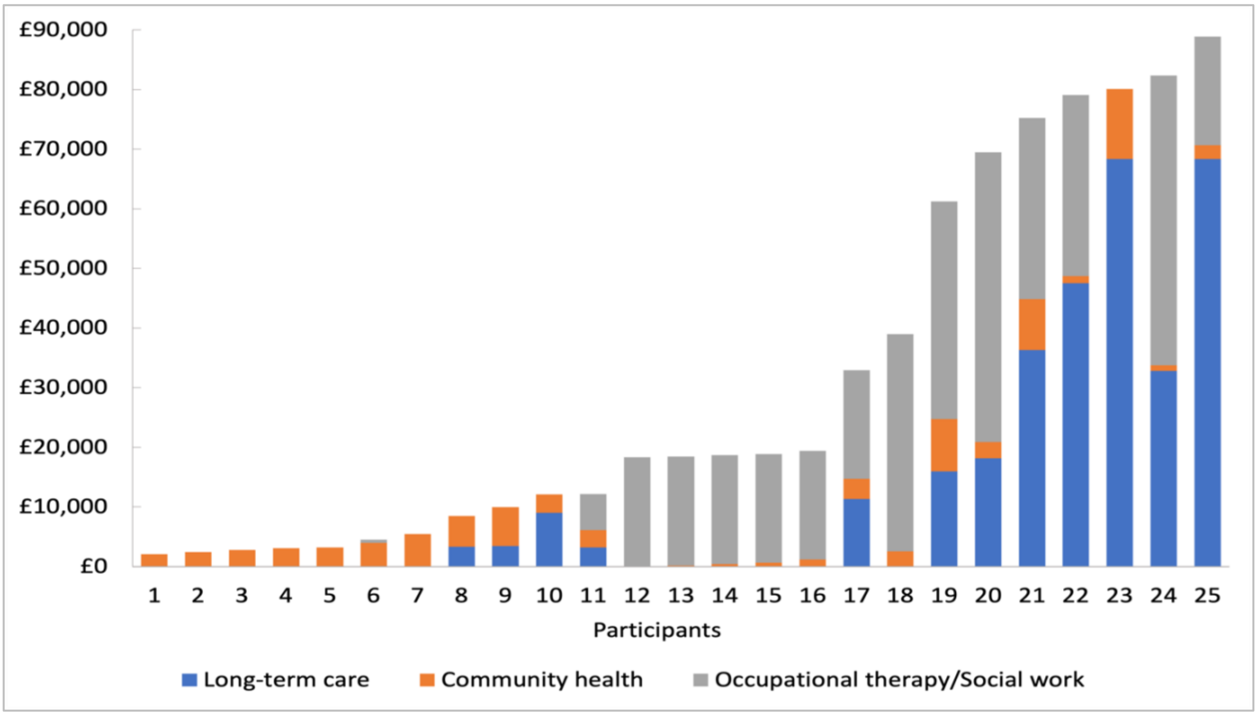

Figure 5.6 Total annual care costs (£) by participant (upper OT/SW estimate)

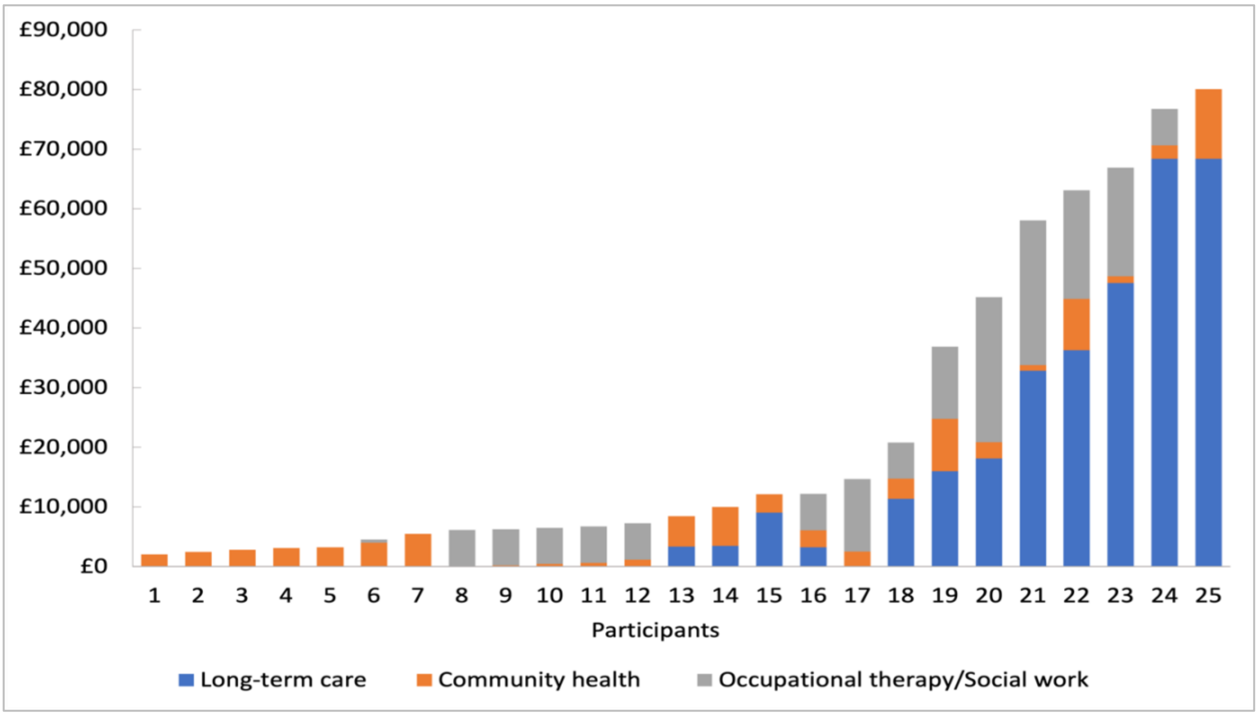

Figure 5.7 Total annual care costs (£) by participant by sector (lower OT/SW estimate)

The BMI ≥70 kg/m^2 group had fewer participants (*n*=3), limiting analysis. It also differed from other BMI groups, with participants sharing the characteristics of severe leg lymphoedema, being mobile at home, and slightly younger (mean age 57 years) (Table 5.2). BMI groups 40-49 (*n*=8), 50-59 (*n*=9), 60-69 (*n*=5) kg/m^2 were more mixed in terms of clinical presentation, age, and functional limitations. Greater numbers also enabled better comparisons, making these groups the focus of costing analyses by BMI group.

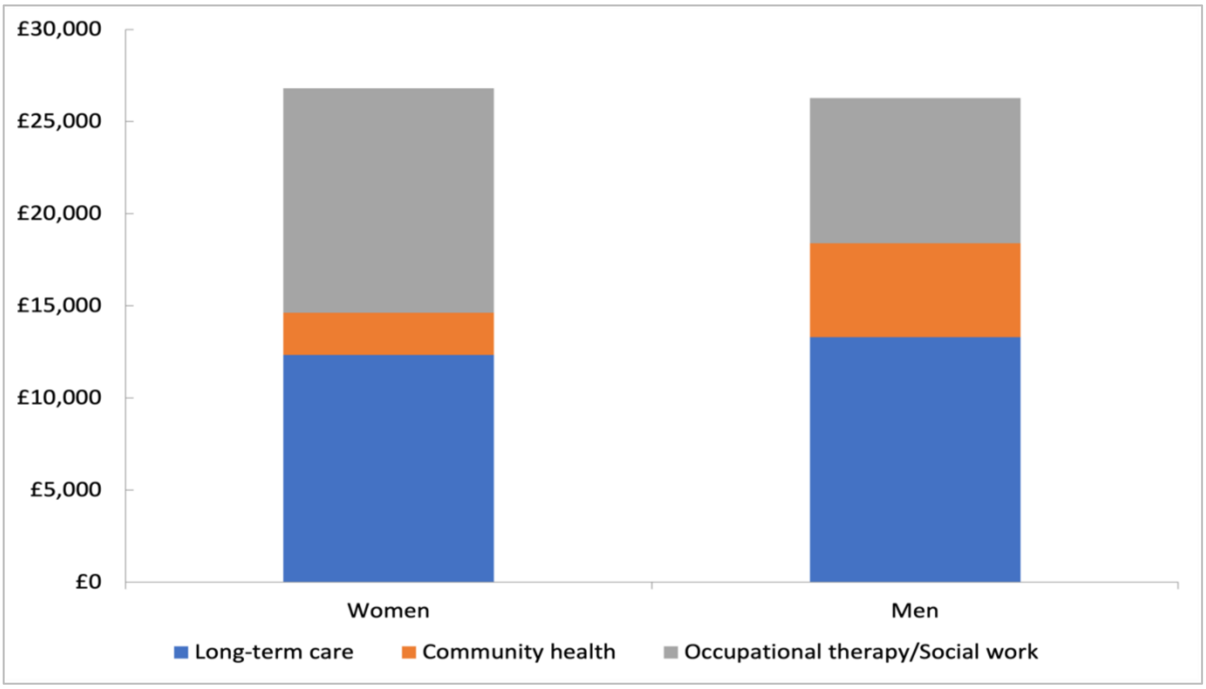

Figure 5.8 Mean annual care costs (£) by sex

Mean community healthcare costs were largely similar across the BMI 40-49, 50-59 and 60-69 kg/m^2 groups at £3,496-£3,694, with BMI ≥70 kg/m^2 costs lower at £2,128 (Figure 5.5). For all participants, men had more than double the mean community healthcare costs of women at £5,095 vs £2,290 respectively (Figure 5.8), primarily driven by receiving insulin therapy for diabetes from district nurses. Mean LTC costs for women and men were similar (£12,329 vs £13,287). Women had higher mean OT/SW costs than men (£12,186 vs £7,897), but the higher mean healthcare costs for men meant total mean costs were similar (£26,805 and £26,279 respectively).

Individual LTC costs for care home residents (£68,364) were nearly double the maximum LTC costs for planned home care services (£36,288). This affected two participants, both in the BMI 50-59 kg/m^2 group, skewing mean totals considerably upwards (Figure 5.5). Sensitivity analysis replacing care home costs with maximum and mean home care costs (£36,288 and £18,108, respectively) showed an increase in mean LTC costs by ascending BMI group when analysed across all participants (Figure 5.5). This increase carried through to total annual mean cost when using maximum home care costs but not mean home care costs. Analysis of LTC users only, intensified costs markedly, such that mean total costs for all LTC users were more than four times that of participants with no LTC use (£45,931 vs £8,745) (Figure 5.9). Across all participants, mean annual cost per participant was £26,594, rising to £45,931 for analysis of LTC users only.

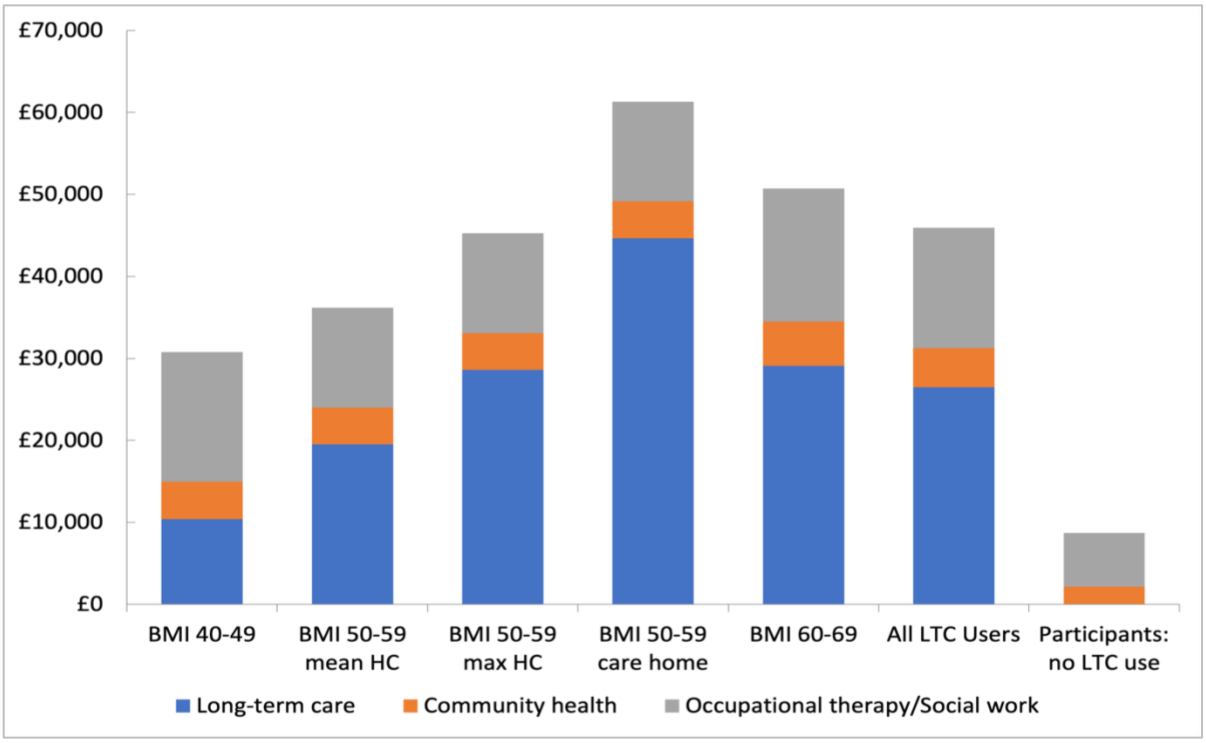

Figure 5.9 Mean annual health and long-term care costs (£): Long-term care users by BMI group and participants with no long-term care use

Legend: LTC=long-term care, HC=home care costs, max=maximum, BMI (kg/m^2).

Mean LTC costs for participants from SIMD deciles 1-5 (£15,299) were double that for those from SIMD deciles 6-10 (£7,214) (Figure 5.10), partially driven by care home costs being included in the former. Sensitivity analyses using mean and maximum home care costs instead, found that even without these, mean LTC costs remained greater for SIMD 1-5 (£9,387 using mean home care; £11,526 using maximum home care), although to a lesser extent, with total mean costs more similar for both SIMD groups. In contrast, mean OT/SW costs were slightly higher for SIMD 6-10 than SIMD 1-5 (£12,150 vs. £9,680, respectively) largely because these participants had input from both OT & SW.

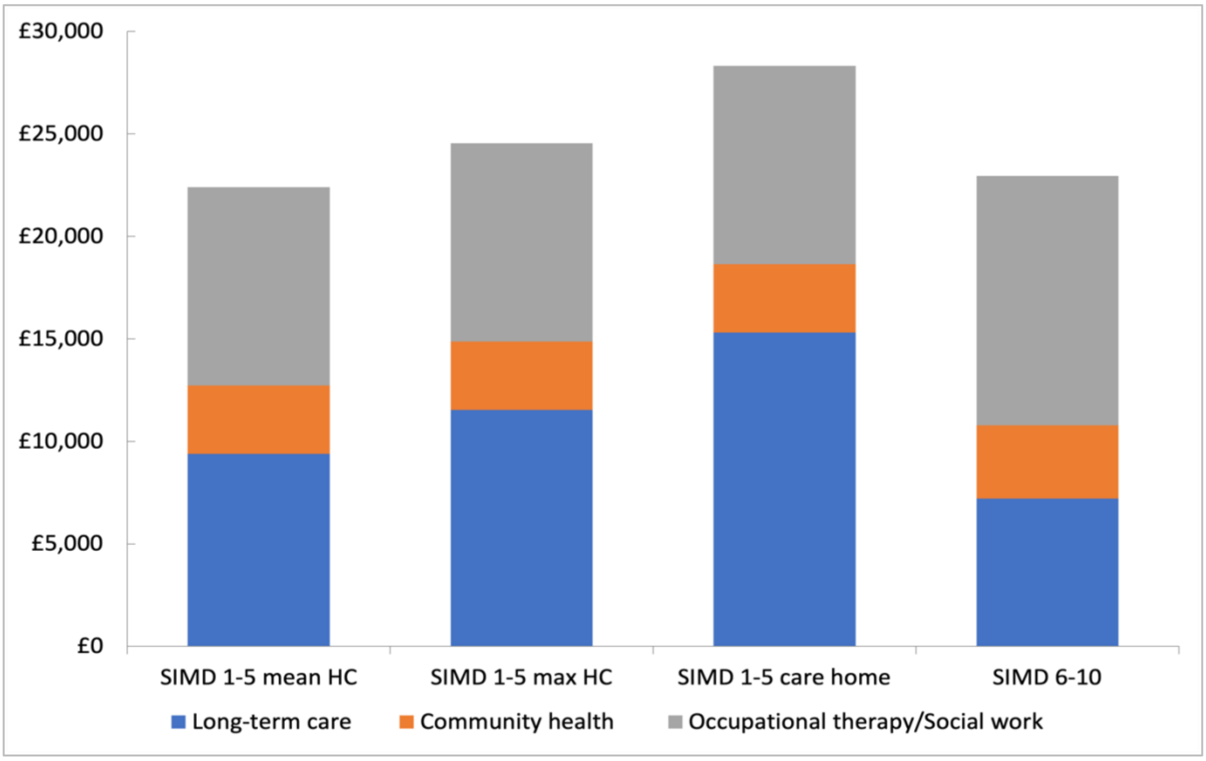

Figure 5.10 Mean annual health and long-term care costs (£): All participants by Scottish Index Multiple Deprivation decile (1=most deprived)

Legend: LTC=long-term care, HC=home care costs, max=maximum, BMI (kg/m^2).

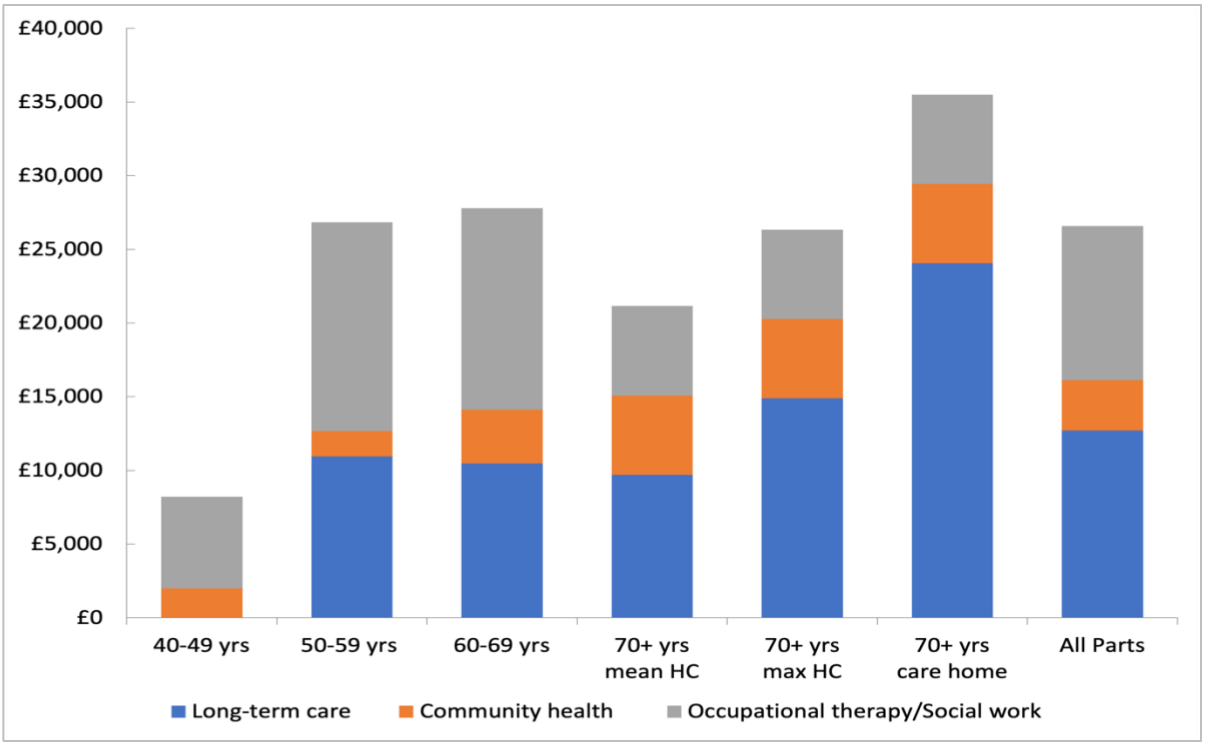

Figure 5.11 Mean annual health and long-term care costs (£): All participants by age group

Legend: LTC=long-term care, HC=home care costs, max=maximum, yrs=years, BMI (kg/m^2).

The proportion of participants using LTC increased by age group, 40-49 years had 0%, 50-59 years had 33%, 60-69 years had 50% and 70+ years had 86%. Again, care home costs, concentrated in the 70+ years group, potentially skewed mean annual LTC costs when analysed as a whole group (Figure 5.11). However, analysis of mean cost by LTC users only, found participants aged 50-59 years had the highest mean costs (£32,832) (Figure 5.12), combining with high OT/SW costs (£30,375), to give the highest total mean costs (£65,157).

All participants had equipment or home-adaptations: 24 (96%) had some or all funded by health or local authority services and one participant sourcing them privately. Specialist, size-appropriate (often termed bariatric) equipment was used by 19 (76%). Rise-recline chairs to aid participants' mobility were the most common equipment, with 20 chairs between 19 participants. Twelve (60%) of these were heavy duty, another four (20%) were custom made, two (10%) were privately supplied (not included in costs), and two (10%) were standard issue. Equipment costs ranged from £0-£25,495 by participant (mean £4,585 for all, median £2,367), with 10 participants having individual costs >£5,000.

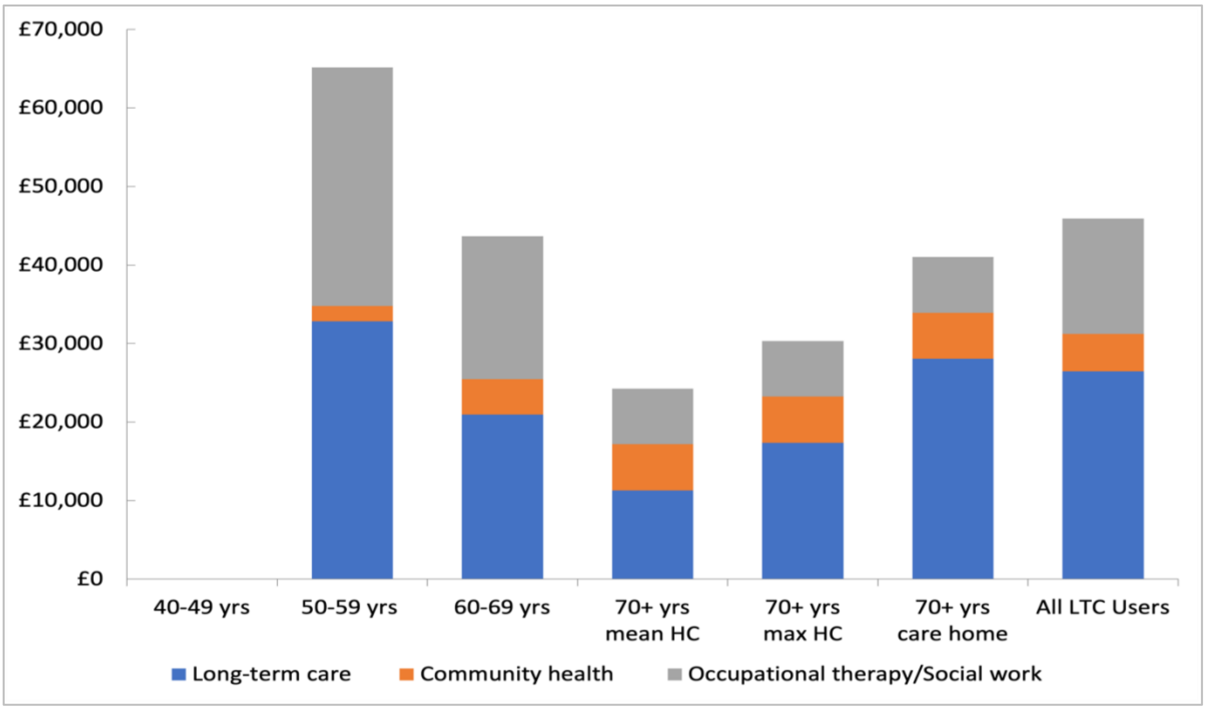

Figure 5.12 Mean annual health and long-term care costs (£): Long-term care users only by age group (years)

Legend: LTC=long-term care, HC=home care costs, max=maximum, yrs=years, BMI (kg/m^2): 40-49 years had no long-term care users hence no data displayed.

Housing adaptations ranged from simple bathroom grab rails to full-scale house extensions involving architects and builders, with costs from £0-£30,576 by participant (mean £5,368, median £412). Twelve (48%) participants had individual costs >£5,000. Sixteen (64%) participants had access to wet floor showers, 10 (40%) being verifiable adaptations by the local authority or a housing association, two (8%) in care homes, two (8%) privately installed, and two (8%) already existing in properties.

5.6 Discussion

5.6.1 Summary of key findings

This study evidences the wide spectrum of community care services, with associated costs, needed to support people with severe obesity living in the community. Utilisation of key services, notably community nursing, OT and LTC, was often long-term, and commonly included people aged <65 years. Crucially, the greatest costs were for OT/SW and LTC, principally funded in the UK by local authorities, rather than the NHS. Whilst costs for both LTC and OT/SW input appear large, it is notable that the LTC costs presented are robust and recurring (mean 22 months), whilst the OT/SW costs contain some uncertainties due to staff time being poorly documented and annualising of shorter episodes (mean eight months). Economic evaluations of obesity and weight management need to include these wider care costs to ensure completeness. Basic analysis suggests ascending BMI group plays a role in increasing costs, but larger, more sophisticated studies are needed.

Non-essential community health services including podiatry, physiotherapy, mental health, and weight management virtually ceased in-person service delivery at the start of the Covid-19 pandemic, shortly after data collection began. Essential services, including district nursing and LTC continued in-person, albeit with restricted input. This frequently meant participants or informal carers undertook extra tasks such as wound and skin care, meal preparation or medication administration. Therefore, service utilisation as documented represented the minimum care provision possible, deemed essential, unable to be deferred or managed remotely. Consequently, despite robust methodology, community health and LTC costs are almost certainly underestimated.

Costs generally reflected patterns of utilisation, with three groups broadly definable (Figure 5.4): a lower cost group (<£6,000) using solely community health services, a medium cost group (£8,000-£13,000) mainly using services from two sectors (community health and LTC, or community health and OT/SW costs) and a higher cost group (£26,000-£82,792) using services across all three sectors of community health, LTC, and OT/SW staff. This raises interesting questions about how severe obesity impacts community service utilisation, particularly if, and how, progression occurs from the lower cost group to the higher cost group. Future research could explore how the duration and severity of obesity affects an individual's functional limitations and subsequent need for care. A natural extension could consider the potential of weight management interventions to improve functional status, subsequent need for care, and importantly quality of life measures.

5.6.2 Long-term care utilisation

The findings support previous evidence from population studies demonstrating that severe obesity is associated with high LTC utilisation and costs (Gousia et al., 2019, Nizalova et al., 2018, Felix et al., 2015). However, research to date is limited by using older data (2002-10), exclusion of those <65 years, or in care homes, and low numbers of people with severe obesity (Copley et al., 2017, Gousia et al., 2019, Nizalova et al., 2018, Felix et al., 2015). This study extends the data by including all adults, with the finding that 56% of all participants and 25% of participants receiving LTC were <65 years. The finding reflects the bidirectional relationship between obesity and disability (Matizanadzo and Paudyal, 2021), with prevalence of severe obesity amongst adults with disability being double that of adults without disability (11.8% versus 5.4% respectively) (Ministry of Health New Zealand, 2022).

Increasing prevalence of severe obesity across younger age groups (Scottish Government, 2020a, NHS Digital, 2020b, Stierman et al., 2021), with rapidly rising levels in children (NHS Digital, 2021) means consequences of severe obesity may be occurring earlier than previous generations. Additionally, individuals with severe obesity are at increased risk of a fall or stroke (Bray et al., 2017), leading to immediate serious functional limitations. Community services need to plan for increasing numbers of adults with severe obesity across all ages, needing LTC care. Currently, appropriate community service provision for this population is often lacking (Felix et al., 2016, Schuldt et al., 2021).

5.6.3 Numbers affected

Unfortunately, service pressures prevented some services (notably physiotherapy and podiatry) from responding to the study, rendering census data incomplete. However, weight management and lymphoedema services identified a further 229 (171 and 58 respectively) individuals. The census data indicated that the participants are broadly representative of a wider population using services (Appendix 2, Table 3). Indeed, when compared with participants, the higher proportion of non-participants with SIMD 1-5, may signal a greater burden of physical and mental illness associated with lower socioeconomic status (McLean et al., 2014). This likely includes acute illness or inability to consent due to cognitive decline or learning disability (both contraindications for participation). Such factors are themselves associated with raised BMI and independently likely to result in increased service utilisation and costs (Gearon et al., 2020), again suggesting that the study findings represent conservative figures.

Further studies are required to establish the number of people with severe obesity who require community health and LTC services across the life course. General weight recording in primary care is problematically low, with approximately one third of patients having weight recorded annually (Nicholson et al., 2019). Population surveys struggle to adequately document people with severe obesity (Williamson et al., 2020). Consequently, robust data on numbers of community-dwelling individuals with BMI ≥40 kg/m^2 is lacking. Application of current Scottish BMI ≥40 kg/m^2 prevalence rates (Scottish Government, 2020a), by age and sex to area population data (National Records of Scotland, 2021b) produced an estimate of 4,500 people per 100,000 adults for the local authority area studied. Future research needs to disaggregate the BMI ≥40 kg/m^2 population into subpopulations (Grieve et al., 2013), given the wide BMI range found in this study, with potential differences in service utilisation by ascending BMI group.

5.6.4 Role of weight management

Outcomes of poor quality of life (Forhan and Gill, 2013) and functional limitations (Forhan and Gill, 2013), with potential for high costs of care over sustained periods as evidenced here, make improving access to weight management interventions essential. Accordingly, the finding of low engagement with NHS weight management is particularly relevant. This was not explained by eligibility criteria for referral, as all participants exceeded the BMI criteria for weight management referral. The finding is consistent with studies suggesting a complex picture around underutilisation of weight management services by people with severe obesity, including lack of services for housebound individuals and need for improved education of health professionals (Holt and Hughes, 2020). Census data from the weight management service showed a significantly differing demographic profile from the other groups, being predominantly women (78%), and markedly younger (mean 45 years) (Appendix 2 Table 3). This suggests a different cohort receiving weight management from those receiving community health and LTC service. Consistent with this, a 2019 British Psychological Society report highlights “an emerging cohort” (British Psychological Society, 2019) of housebound people with BMI ≥50 kg/m^2 for which

> *“healthcare staff are struggling to meet patient need and are unable to provide reasonable alternatives of care” (British Psychological Society, 2019).*

The increase in remote weight management services resulting from the Covid-19 pandemic may offer future development potential for this under-served population (Ross et al., 2022), as do the new wave of effective anti-obesity medications (Ryan, 2021). Importantly for this population, shifting away from a weight-centric approach to one focused on wider person-centred outcomes (Wharton et al., 2020), including maintaining or achieving functional independence, potentially holds benefit for both individuals and service providers. Training for community staff, who often have sustained input with clients, but feel ill-equipped to discuss weight (Zevin et al., 2021), could lead to health gains.

5.6.5 Strengths and limitations

This study's strength is its robust presentation of real-world evidence, to the authors' knowledge not available elsewhere, of detailed community health, OT/SW, and LTC service utilisation and costs. For researchers who may not be familiar with community services, it highlights the type of services that need further research, alongside methodology for micro-costing. Hopefully the resultant visibility of OT, district nursing, and LTC services will encourage further research, ideally through collaboration with practitioners.

A potential limitation is that service usage, and hence costs, were not solely attributable to severe obesity (York Health Economics Consortium, 2016). Participants had multiple other comorbidities, some related to raised BMI including lymphoedema, stroke, cardiovascular disease and diabetes (Bray et al., 2017). Other comorbidities appeared independent of raised BMI such as multiple sclerosis, spina bifida and ulcerative colitis. Collecting data on all medical comorbidities was outside the study's scope but, where disclosed by the participant as relevant to the help needed at home, these were noted. This included verifiable data for all participants regarding diabetes status, with nine (36%) having Type 2 diabetes. Notably for LTC services, service utilisation is arguably a broad proxy indicator of functional limitation, commonly mediated by presence of an informal carer (Nizalova et al., 2018). Future studies to estimate attributable costs could use regression methods with cohorts of those with and without severe obesity, matched for sex, age, socioeconomic status, and chronic disease.

A further limitation is the small number of participants, limiting examination of associations between variables.

5.7 Conclusion

People with severe obesity, including those under 65 years, may need multiple, long-term, or episodic, costly inputs from community health, OT/SW, and LTC services. This care needs to be recognised in cost of obesity studies and economic analyses of weight management interventions. Service providers need to plan for the specialist needs of this increasing population, particularly the housebound.

Chapter 6 Results Qualitative “It would help if… professionals could understand what difficulties big people have”. A qualitative study of the experiences of people with severe obesity who use community health and long-term care services

This chapter is unpublished but written as a manuscript for submission to Health and Social Care in the Community.

Contributions:

KW conceived and designed the study, carried out data collection, data analysis and interpretation, and wrote the manuscript. DNB supervised data analysis and interpretation and edited the manuscript. MEJL conceived and designed the study, supervised data collection, and reviewed the manuscript.

6.1 Overview

This chapter clearly answers research question 5:

- What are participants’ experiences of using health and social care services?

However, its reach is wider than this, as due to the interviews being semi-structured, with interview questions intentionally broad and open-ended (see Appendix 3 for interview schedule) participants related their wider lived experience which was the context for their service utilisation. Due to the purposive sampling, participants all had need for formal help from health and care services, many requiring significant assistance with ADLs on a long-term basis, due to limited function associated with disability. This represents a specific sub-population of people with severe obesity, but one that is poorly documented in the literature.

Lived experience of people with severe obesity has received increasing attention in recent times, but frequently from the perspective of those seeking health improvement (Imhagen et al., 2022, Haga et al., 2020, Ueland et al., 2019), weight management treatment (Farrell et al., 2021), inpatient healthcare experience (Pazsa et al., 2022, O'Donoghue et al., 2021a) or who experience less functional limitation and are still active outside the home (Ellison et al., 2020). Thus, this work fills a gap in the evidence base, particularly to inform service development for this subpopulation.

However, what is noticeable when comparing this study’s findings with the wider evidence base is the degree of similarity in the characterisation of the lived experience, particularly where studies have focussed on those with BMI ≥40 kg/m^2, rather than BMI ≥30 kg/m^2. Issues around lack of facilities and equipment, resulting in social isolation are common. Also the sense of the individual waiting to live their real life without the limitation of excess weight. Poor quality of life and mental health outcomes are unsurprising in such circumstances (Emmer et al., 2020). The need for change is clear.

6.2 Abstract

Introduction

Evidence indicates growing demand on community health and long-term care (formal home care and care home) services by people with severe obesity (BMI ≥40 kg/m^2), often due to functional limitations. The experiences of people using such services are largely unexplored.

Aims

This qualitative study aimed to explore the lived experience of people with severe obesity who use community health and long-term care services.

Methods

As part of a larger mixed-methods study, community-dwelling people with severe obesity in receipt of community health and long-term care services were recruited via community professionals and visited at home. Participants consented to individual, audio-recorded, semi-structured interviews, which were transcribed and analysed using thematic analysis.

Results

Nine women and three men (*n*=12) participated, aged 40-76 (mean 60) years, BMI ranged from 45-74 (mean 59) kg/m^2, eight were housebound. Three overarching themes were identified. Firstly, the hidden struggles of living with a larger body affected all participants, including functional limitations affecting mobility and personal care. These contributed to a sense of being stuck physically, socially, and biographically, partially due to poor treatment options. A second theme found explicit weight bias was commonly, but not wholly, denied. However, most participants related implicit weight bias by a system structurally unprepared to care for people with severe obesity. The majority of participants showed strong internalised weight bias, linked to shame and self-blame for their poor function and larger bodies. Thirdly, a day-to-day coping theme highlighted strategies

regularly used by participants: resigned acceptance, avoidance and denial, exercising choice, and support from informal carers.

Conclusions

Participants experienced unmet physical and psychological care needs associated with their larger bodies, leading to poor quality of care and life. Given rising prevalence, changes to care services are required. Specific recommendations include staff training about needs of people with severe obesity, ensuring the physical infrastructure of care services can safely accommodate people with severe obesity, and improving access to effective, person-centred weight management treatments.

6.3 Introduction

Although often poorly documented, prevalence of severe obesity (Body Mass Index (BMI) ≥40 kg/m^2) is rising internationally (Williamson et al., 2020). United States (US) data shows this BMI category having the largest proportional rise since the 1980s, with prevalence for women now over 11% (Stierman et al., 2021). Prevalence of severe obesity for people with disability is twice that of people without disability (Ministry of Health New Zealand, 2022). Thus, people with severe obesity are likely to be over represented in the use of health and long-term care services, with both hospital and community staff reporting increasing numbers using services (Lumley et al., 2015). Additionally, the increasing prevalence in children and young adults (16 to 24 years) (Stierman et al., 2021, NHS Digital, 2020b, NHS Digital, 2021), means that the functional limitations associated with severe obesity (Kyrou et al., 2011) may in the future be experienced earlier than in previous generations.

Given this context, community-dwelling adults with severe obesity, particularly those who are housebound, can need multiple essential community health services aside from family physicians, such as occupational therapy (OT), district nursing, physiotherapy, and podiatry over many years (Williamson et al., 2022a) although this is sparsely documented. When these services no longer suffice or are unavailable, growing international evidence shows rising demand for residential care and formal home care services, known as social care in the United Kingdom, but often termed long-term care elsewhere (Hales et al., 2020a, Zhang et al., 2019a, Schuldt et al., 2021, Gousia et al., 2019, Parkinson and Thompson, 2021, Williamson et al., 2022a).

The lived experience of people with obesity (BMI ≥30 kg/m^2) has received increasing attention in recent years, although less so for people with severe obesity (Farrell et al., 2021), despite larger body size increasing the risk of functional limitations (Vincent et al., 2010). Studies primarily focus on those accessing weight management, particularly bariatric surgery (Farrell et al., 2021, Garip and Yardley, 2011). This is true even when the study focus is not weight management (Owen-Smith et al., 2014). Yet over 58% of people with severe obesity have no record of weight management intervention (Booth et al., 2015), with a tiny fraction of those eligible receiving publicly-funded bariatric surgery (Gulliford et al., 2016, Dona et al., 2022). Consequently, the views of non-weight management seeking individuals, constituting the majority of the population affected, are likely under represented by current evidence (Robertson et al., 2022).

This gap in the evidence is significant given that the consequences of excess weight mean people with severe obesity are more likely to use wider health and care services (Espallardo et al., 2017), which may struggle to accommodate them (Schapiro, 2021). Research relevant to community practitioners is generally lacking in the biomedical literature (van Weel et al., 2012). This is particularly true regarding the perspective of users, especially housebound individuals, who comprise a seldom-heard population in health and long-term care research (Ní Shé et al., 2019), largely excluded from weight management (Holt and Hughes, 2020). Thus, other than one small (*n*=6) 2006 study looking at the experience of those weighing ≥150 kg and using ≥1 assistive device (Pain and Wiles, 2006), the lived experience of people with severe obesity using community services is largely unexplored.

There is a growing evidence base documenting service provision challenges experienced by care professionals when trying to provide quality care for people with obesity (Agaronnik et al., 2021, Lumley et al., 2015, Hales, 2018, Hales et al., 2019a, Parkinson and Thompson, 2021, Williamson et al., 2022b, Bradway et al., 2016, Wiles et al., 2017, Dockrell and Hurley, 2020, Woods et al., 2016, Ellison et al., 2020, Lunt et al., 2022, Hitch et al., 2020). However, understanding people’s lived experience can identify aspects of life unknown to professionals (Ueland et al., 2019, Johnstone et al., 2020) providing impetus and insight to holistically improve the quality and effectiveness of care (Fade, 2003). This is particularly important given evidence of weight stigma and bias by health professionals towards people with obesity, resulting in reduced quality of care provision (Phelan et al., 2015, Pazsa et al., 2022).

For people with obesity, the lived experience of weight stigma or bias is receiving increasing attention both as a cause and consequence of obesity, with increasing BMI associated with increased weight stigma and poorer mental health (Emmer et al., 2020). Weight bias – negative beliefs associated with excess weight - can be explicit, where attitudes are conscious and overt, or implicit, with automatic, unconscious reactions, that often link characteristics with specific attributes in an unrecognising manner (Lydecker et al., 2018, Carels et al., 2010). People with excess weight can experience both forms of bias from others (Carels et al., 2010), alongside internalised weight bias (IWB), where negative beliefs about weight are applied to the “self” (Bidstrup et al., 2022). All three forms of weight bias (explicit, implicit, and internalised) can be barriers to an individual’s engagement with services, and therefore require active consideration by service providers (Alberga et al., 2019).

6.3.1 Study aims

Using a qualitative approach, this study aimed to explore the lived experience of people with severe obesity living at home, or in care homes, who use community health or long-term care services.

6.4 Methods

6.4.1 Setting

A Scottish local authority area, broadly representative of the Scottish general population by age and long-term health conditions (National Records of Scotland, 2021a).

6.4.2 Participant selection

This nested qualitative study was part of a larger study exploring use and cost of community health and long-term care services by people with severe obesity (Williamson et al., 2022a). As documentation of BMI in community care can be poor, purposive sampling was used. Potential participants were given brief verbal information about the study by community professionals, before giving their permission to be contacted by the investigator. Eligibility criteria were: adults aged 16 years and over, in receipt of care services, able to provide informed consent, and likely to have a BMI ≥40 kg/m^2. Exclusion criteria were: individuals that professionals identified as a safety risk for a home visit (e.g. known aggression towards staff) or where study participation could cause undue stress or distress. Sample size was dictated by the number of participants willing to be interviewed and achieving a broad mix of service utilisation, by BMI range (≥40 kg/m^2) sex, and age across the whole sample.

6.4.3 Data collection

Participants were visited at home by the lead investigator (KW), who obtained written informed consent prior to taking anthropometric measures (Williamson et al., 2022b) and completing a “Help at Home” questionnaire gathering quantitative data on service utilisation, reported elsewhere (Williamson et al., 2022a). Participants were offered the opportunity to undertake an audio-recorded semi-structured interview, with those who completed both the quantitative and qualitative parts of the study receiving a £10 shopping voucher in appreciation of their time. Participants were also given an information postcard about Obesity UK, a peer obesity advocacy group, representing a relevant peer support network, of potential interest. Interviews, lasting between 10 and 72 (mean 35) minutes, were guided by a topic guide (Appendix 3), based on broad areas of interest, followed by more focussed follow-up questions (Lochmiller, 2021). All study materials were piloted with two people with severe obesity (including a representative of Obesity UK) for tone and content (Serrano-Fuentes et al., 2022), with subsequent minor revisions. As interviews were home-based, some participants, at their choice, had family members present, who also contributed to varying degrees.

Data collection occurred between February and December 2020, largely coinciding with the early months of the Covid-19 pandemic and resulting in modifications to the data collection plan. Prior to Covid-19, the investigator planned to attend separately from clinical services, to facilitate participants giving honest feedback. The pandemic, and subsequent lockdowns, both limited face-to-face contact and put essential clinical services under increased strain. Accordingly, where able, the investigator, a district nurse, fulfilled essential care duties for participants at the same visit as conducting the interview. This meant the investigator being more closely aligned with clinical services than originally planned. It also meant applying National Health Service (NHS)-approved Covid-19 mitigation measures, including social distancing from the participant, limiting overall duration of visit and wearing personal protective equipment, including face mask. These measures negatively impacted verbal and non-verbal communication.

All participants were in a high-risk category for Covid-19, with many shielding, compounding the social isolation often experienced by housebound individuals. Thus, the opportunity for face-to-face contact with the investigator appeared welcome by some participants, who were keen to talk. No participant declined to answer any questions, despite this option being specifically offered. If participants expressed distress, they were offered the opportunity to pause, or stop, only proceeding when they chose. Prior to interview, participants were advised of confidentiality, except for General Practitioner involvement in case of a serious harm disclosure (Appendix 3).

6.4.4 Reflexivity

The investigator identified as an NHS-employed district nurse professional both in Participant Information Sheets given to individuals considering participation and in physical presentation, wearing a nurse’s uniform. Some participants had previously met the investigator in a nursing or manual handling role.

The project represented a doctoral study for the investigator, motivated by past clinical experience of caring for people with severe obesity with minimal evidence base and poor outcomes (Williamson et al., 2022c). Personal characteristics of the investigator were female, BMI within range 18.5 to 24.9 kg/m^2, age 45 to 55 years, with no obvious physical disabilities. Personal experience related to body size was being overweight in the year post-pregnancy, exacerbated by medication, with subsequent weight loss (Warin and Gunson, 2013). Previous experience of qualitative methods included a Masters dissertation using semi-structured interviews. Outcomes were shared with advocates of people living with obesity to check for unconscious bias in presentation.

6.4.5 Data management

Audio-recordings were stored securely on password protected drives on the NHS network. Interviews were transcribed verbatim by KW. Pseudonyms were allocated to participants, with identifying names of place or people removed. Pseudonymised interview transcripts were securely transferred to the University, with the pseudonymisation code remaining separate in the NHS.

6.4.6 Data analysis

Interviews were entered into NVivo (qualitative data management software) (Version 12), where they were analysed inductively, using a reflexive thematic approach (Braun and Clarke, 2022). Analysis was led by KW, in collaboration with DNB as supervisor with expertise in qualitative methods. Analysis followed an iterative process, with immersive reading of the interviews leading to a coding framework. The subsequent coding framework was discussed with DNB, who also checked a sample of coding to establish coding reliability. Detailed coding was undertaken by KW, systematically going through the dataset, multiple times. The coding framework was then considered for patterns of commonality, distinction and connection, identifying broad emergent themes and subthemes, named to encapsulate their “essence” (Lochmiller, 2021). The study was reported according to the Consolidated criteria for Reporting Qualitative Research (COREQ) guidance (Tong et al., 2007).

6.4.7 Theoretical framework

The study was underpinned by a critical realist ontology, using an epistemology of contextualism (Braun and Clarke, 2022). This was considered appropriate given that severe obesity is an existential reality for individuals, but that responses to it are relative to, and shaped by, societal and individual context, particularly attributions about cause. Critical realist reflexive thematic analysis encompasses “situated realities”, acknowledging the “limits and constraints of the world participants exist within” (Braun and Clarke, 2022, p171). This seemed fitting for work regarding help needed by those living with a larger body, particularly for examining the experience of housebound individuals. Contextualism recognises the role of the researcher in relationship with the participant, shaping the knowledge produced. This is significant given the investigator’s nursing background, which provides the wider context for the study, thus needs recognised.

6.4.8 Ethical considerations

NHS Research and Development and South-East Scotland Ethics service deemed the project service evaluation, with approval from the University of Glasgow Medical, Veterinary and Life Sciences Ethics Committee (Project Number 200180200) (Appendix 4) as a doctoral study. The local Caldicott Guardian oversaw data governance approvals.

6.4.9 Note regarding terminology

No single term is acceptable to all stakeholders when discussing weight-related body size (Hales et al., 2019b). ‘Severe obesity’ has been used thus far, given its wide usage in the health-related literature, although ‘living with higher weight’ was used in study paperwork, as people with lived experience reviewing materials found this less medicalised. However, both the participants and the wider critical literature informing discussion of the results, include broader perspectives on body weight, choosing to use different terms, such as ‘fat’ and ‘larger-bodied’, that are more meaningful to their given perspective (Murray, 2007). Thus, to be inclusive of these different perspectives, a range of terminology is used for the rest of the paper.

6.5 Results

Twelve people (nine women and three men) agreed to be interviewed, of whom eight were housebound. Participant characteristics are summarised in Table 6.1. Three overarching themes were identified: 1) Hidden struggles of living with a larger body, 2) Experience of weight stigma and bias, and 3) Day to day coping strategies used by participants. Each theme had subthemes summarised in Table

6.2. For context, illustrative quotes are labelled M or F for male and female respectively, with a study number corresponding to the individual participant, their age range and indicator around mobility, as factors potentially relevant to their lived experience.

Table 6.1 Summary of qualitative participants' characteristics

	Age (yrs)	Fe male (%)	BMI (kg/m^2)	SIMD[1]	Indoor mobility	House-bound (%)	Reported medical conditions	Lived with	WM input	Referred by
Range	40-76	9 (75)	45-74	2-9	Ambulant unaided:3 Ambulant walking aid:5 Chair bound:2 Bed bound:2	8 (66)	Depression, anxiety, falls, lymphoedema, peripheral vascular disease, ulcerative colitis, spina bifida, multiple sclerosis, registered deaf, vasculitis, stroke, Peripheral neuropathy, Bell's palsy, urinary incontinence, COPD, agoraphobia.	Partner/ husband/wife: 5 Teenage child:2 Grown up child:2 Parent:1 Alone:1 Care Home:1		
Mean	60		59	5						
Comments			40-49:2 50-59:4 60-69:4 70+:2	1-5:7 6-10:5					Yes:1 Waiting list:3 Past:4 No: 4	OT:4 DN:7 Dietitian: 1

Legend: BMI, Body Mass Index; SIMD, Scottish Index Multiple Deprivation; COPD, Chronic Obstructive Pulmonary Disease; OT, Occupational Therapist; DN, District Nurse; WM, Weight Management

Table 6.2 Summary of qualitative themes and subthemes

Themes (Subthemes)	Summary
1. Hidden struggles of a larger body	Unlikely to be known to people without severe obesity; often shame provoking; not easily solved, lead to "intertwined complexity"
• Restricted function – personal care	Challenges with washing, dressing, and intimate personal care at least partially due to body shape or size; included those relatively young and mobile; the need for assistance was seen as hidden and frequently shame-provoking; voiced desire for independence.
• Restricted function - mobility	Affected people differently: body size either restricted movement (walking, bending over) or made assistance (from others or equipment) more complex; staff capacity and equipment for larger bodies often lacking; poor input felt to impact function and quality of life; feelings of shame about dependence.
• Sense of being stuck	Multiple layers: physically, socially and biographically stuck. Associated with feelings of frustration and poor quality of life.
2. Experiences of bias and stigma	
• Explicit stigma denied	Largely denial of explicit stigma from staff, with some limited examples. When care was demanding for staff due to weight or size, blame could be implied.
• Implicit weight bias	Reduced quality of, or access to, care due to body size. Poor awareness by services/staff about needs of people with larger bodies. Equipment too small.
• Internalised weight bias	Negative beliefs about people with larger bodies, directed towards themselves, included self-limitation, low confidence, explicit bias against other people with severe obesity, body shame, and self-blame.
3. Day to day coping regarding living with a larger body	
• Resigned acceptance	Particularly by people living with severe obesity for many years.
• Avoidance and denial	Avoidance of acknowledging body size, or situations seen as stigmatising. For those who were bed bound this meant going to sleep.
• Exercising choice	Taking positive action, exerting some control, even in constrained circumstances.
• Informal carers	Helped manage the challenges of daily life including personal, often intimate care, providing emotional and social support, and coordinating care. Impactful on carers in terms of burden of care.

6.5.1 Hidden struggles of living with a larger body

This was the predominant theme, widely shared by participants, encapsulating much of their daily lived experience. Hidden struggles were defined in the following ways; being unique to people with larger bodies, thus unknown to people without obesity; often shame provoking, linked to difficulty performing intimate care needs due to body size, for which it may be difficult to ask for help, contributing to negative body image; an individual's weight being seen as under their control; struggles that are not easily solved; culminating in an intertwined complexity, where larger body size had an amplifying effect on disability experienced, weight status and care needed.

6.5.1.1 **Restricted function: personal care**

All participants acknowledged needing help with washing and dressing, toileting, and skin care due to larger body size. Ten participants, including those who were relatively young and mobile, candidly highlighted challenges around intimate personal care needs (such as toileting, skin care to breast and groin area, administration of vaginal medications), at least partially due to body shape and size making it difficult to reach. Where need for help with intimate care was not available, participants risked easily treatable conditions continuing or worsening. Alternatively, participants faced embarrassment and shame receiving help from informal and formal carers, when they wanted to be independent. Professionals appeared unaware of participants' struggles to self-care.

> *M3: "I can do the toilet, but I can't actually wipe myself, you know, so there's a problem there." (M3, 60-70 years, bedbound)*
>
> *F4: "I wish that there was something that you could buy… to help with like washing down below, so I could do it myself, and put on cream myself… I dinnae like having to ask my mum." (F4, 40-50 years, mobile in house)*

6.5.1.2 **Restricted function: mobility**

This subtheme affected all participants to some degree but manifested differently depending on how size and other disabilities affected physical function. Participants' past care journey was also influential. Some participants felt that limited input from physiotherapists and occupational therapists, at critical points, had adversely affected their mobility, subsequently reducing their quality of life. Participants who were chair or bed bound were most affected, depending on others for mobility. This often made moving and handling more complex, including more staff, specialist equipment, more space and extra training. Such requirements commonly brought intertwined complexity to care, with a ripple effect as one element impacted another, causing long delays, with very real limitations for participants' lives. Staff openly named body size as a complicating factor in care, linking it to the theme of weight bias, both explicit and implicit.

> *F1: "if I hadna so much weight I would be walking nae problem." (F1, 50-60 years, walks with aid)*
>
> *F2: "Well, because I can't get out of bed myself, umm, I have to rely on carers to hoist me out. My carers at the moment are having problems because they can't use a hoist. So for months now I've been stuck in bed. All day 24 hours a day, 7 days a week." (F2, 60-70 years, bedbound)*

6.5.1.3 Sense of being stuck

This subtheme reflected three different layers of participants' experience; physically, socially and biographically stuck. Physically stuck particularly related to where participants were chair, bed or housebound. This often limited opportunities for interaction, giving a sense of being socially stuck, with the added aspect of weight stigma from society making some participants limit their social interactions. Biographically stuck related to the wider sense of being stuck in the situation of living with a larger body, and in theory knowing the problem, but in reality, not the answer, to changing their weight status. This sense permeated the narratives of the whole group. The sense of being stuck led to frustration at the lack of solutions available, closely linked with low mood, hopelessness and feelings of poor quality of life, especially for those housebound.

> *M3: "Every other week I have a bit of a downer…I just feel I'm stuck you know. What am I going to do?' (M3, 60-70 years, bedbound)*
>
> *F4: "I'm past it now for help, Kath.*
> *Int: Do you really think that?*
> *F4: (Quietly) Aye, aye. There's nae point. It's… I am 46, like I've missed out a lot on life, em … and I would no' wish this journey on anybody… 'cos this is nae a life, it's an existence, that's what it is really, basically." (F4, 40-50 years, mobile in house)*

The hidden struggles outlined were frequently accompanied by shame for participants about their functional limitations, and need for help, especially where they felt this related to body size. This was evident through feelings of low self-esteem, anxiety, shame or anticipation of shame about their bodies, particularly when expressing the need for help.

> *(talking about the difficulties of cleaning herself (groin/bottom) due to effect of bowel disorder unrelated to obesity)*
> *F8: "I think they look at you in disgust as if to say what? Are you for real? I'm like… aye (very quiet)*
> *Int: Do you feel like you can discuss that with people like…*
> *F8: Oh no!*
> *Int: Your GP?*
> *F8: It's embarrassing!*
> *Int: Right, so you wouldn't bring that up with your GP…*
> *F8: I've mentioned it briefly, but I've not went into detail about it… I get embarrassed…*
> *Int: So actually being able to say what some of your physical issues are is quite hard?*
> *F8: 100%. Yeah." (F8, 40-50 years, mobile)*

6.5.2 Experience of weight stigma and bias

Three different forms of weight stigma and bias were observed: explicit, implicit and internalised.

6.5.2.1 Explicit weight bias

Interestingly, when directly asked if they had experienced explicit stigma from staff, most, but not all, participants said no.

> *Int: "Have you ever experienced negative attitudes from staff about your weight?*
> *F1: Nah. Never.*
> *Int: Never?*
> *F1: Never." (F1, 50-60 years, walks with aid)*

6.5.2.2 Implicit bias

In contrast, participants' narratives commonly related implicit bias. Here people with severe obesity were not explicitly excluded or stigmatised, but were indirectly excluded, through a bias that failed to include and accommodate larger bodies. This was particularly evident with care that was more demanding for staff to perform, due to participants' size or weight, linking to intertwined complexity.

> *M3: "I think that … they didnae want to lift me because I was heavy.*
> *Wife: Is that what you felt?*
> *M3: Yeah*
> *Wife: That's a sort of prejudice." (M3, 60-70 years, bedbound)*

> *Int: "Ok, so being aware of being larger with manual handling for your carers looking after you, have you found that a problem in terms of people referencing your weight becoming a problem? Or being a problem for them? Or no one's really said that directly?*

> *F6: No one has said that directly, but I get the impression that that is – yes." (F6, 50-60 years, wheelchair)*

Most participants described services that were unprepared, unaware of, and unable to care for people with larger bodies. Much of this could be summarised by "size needs space", with physical lack of space or appropriately sized equipment, meaning services struggled to accommodate participants. This both caused distress, and diminished the safety, quality and accessibility of care compared with people living without obesity. A key example involved men using commodes or raised toilets seats, for whom the aperture was not large enough to accommodate their bottom, meaning they had to use bottles for passing urine even when on the toilet seat or commode. Also common, was staff lacking knowledge about caring for people with larger bodies.

> *M2: "Yes, the reason that I use the bottle is because…when I'm sitting on the pan I'm completely over the whole of the hole! So even if I wanted to point my penis down into the hole, I wouldnae get into the hole,*
> *…Because I'm completely covering it." (M2, 60-70 years, walks in house)*

> *F7: "I've to come for an MRI and it says if you are over 20 stone and it sounds ridiculous now, 1 pound over (laughing), but I'd got myself in such a state. …What if I can't fit in it?" (F7, 50-60 years, mobile in house)*

> *F8: "It would help if the GPs especially, and others er, professionals, could understand what difficulties big people have, so they didnae need to be asked. It's what they expect…" (F8, 40-50 years, mobile)*

6.5.2.3 Internalised weight bias (IWB)

Participants mostly held negative beliefs about themselves due to their size, articulating self-blame, at least partially, for being unable to manage their weight and subsequent consequences. This occurred despite clear contributing factors beyond participants' control, such as physical disability limiting physical activity or medication (for example, anti-depressants, high dose steroids) contributing to weight gain. Several mobile participants, physically able to get out, found the shame of having a larger body affected their confidence and self-esteem, making them curtail activities outside the home.

> *F9: "It's my fault. And I think that is why I get angry with myself. Because I think, you know, 'it's your fault you're this size, you were eating sweets in the hospital. You were eating hospital food and you've allowed yourself to get to this ridiculous size.'" (F9, 60-70 years, mobile in house)*

> *F7: "I think your weight holds you back from you doing a lot of things. It does..*
> *Int: In what way?*
> *F7: It's confidence, really. I'll no go swimming… we've been invited to this or that, 'oh, I'm no going there, I'm too fat', it's... you know..." (F7, 50-60 years, mobile in house)*

> *F4: "My anxiety…, yeah, my weight does affect it because it is loss of esteem, very self-conscious Kath." (F4 50-60 years, mobile in house).*

Interestingly one participant with spina bifida, a life-long physical disability that meant her body was outside societal body norms at any weight, differed notably in approach from other participants. In contrast to others, she was more accepting of her body size, with shame largely absent, and attribution around excess weight being more nuanced, acknowledging the significant contribution of fluid in her legs.

6.5.3 Day to day coping strategies

This theme, containing four subthemes, highlighted strategies regularly used by participants to cope day to day: avoidance and denial, resigned acceptance, taking action, and support from informal carers.

6.5.3.1 Avoidance and denial

Participants commonly and actively used behaviours of avoidance or denial to manage difficult situations relating to their larger body. Examples included avoiding mirrors, not going out, not buying clothes or clothes being used to cover, but not adorn their body. Two completely bed bound participants, who experienced the most severe physical limitations with associated poor quality of life, acknowledged sleep as a way of escaping their lived experience.

> *M1: "When you live with a higher weight, it's like if this was a mirror, right? This is what you see (pointing to head upwards). You don't see the rest… Unless I'm in a larger, full mirror and then it kinda hits you…you think 'God, is that how big I have got or how bad it's got?'… I know how big I am, but even then, I still don't. There's part of me that just sees what I want to see." (M1, 60-70 years, mobile in house)*

> *F2: "Well, because I can't get out of bed myself, umm… I can watch the television. I can listen to music, but half the time I just try to go to sleep because I'm fed up." (F2, 60-70 years, bedbound)*

6.5.3.2 Resigned Acceptance

When discussing living with severe obesity most participants articulated feelings on a continuum, ranging from partial acceptance through learning to tolerate to reluctant resignation. This was best captured as resigned acceptance, evident in their attitude to daily adjustments, such as using urinal bottles when unable to use toilet seats. Two participants differed markedly from this broad range; F5 repeatedly emphasised her acceptance of living with a larger body which had been life long, and the adjustments needed. In contrast, F9, who had only recently experienced weight gain, saw her larger body as problematic and unacceptable.

> *F5: "No, I'm just used to it, honestly, I'm just used to it. I've always been overweight… it's not going to come off. I've quite accepted it. I'm all right with it, aye. I'm just used to it! Does nae bother me." (F5, 70-80 years, mobile in house)*
>
> *Int: "Because some people will say I don't see my weight as a problem, actually. It's just part of who I am.*
> *F9: No, I see mine as a major problem…*
> *F9: I hate being this weight." (F9, 60-70 years, walks unaided)*

6.5.3.3 **Exercising choice**

Despite quite constrained circumstances, most participants actively made choices aimed at improving their quality of life. These choices varied hugely from accessing benefits advice groups online to limiting carer input, often reflecting the desire for some control over daily life.

> *M2: "I feel if I'll get it done, it'll be off my own back. I'll get my mind set to get it back walking again. But I'll get it done mysel'." (M2, 60-70 years, mobile in house)*
>
> *Int: "And you said to me that sometimes you sleep in the chair?*
> *F5: Yes I do aye*
> *Int: Tell me about what affects that decision?*
> *F5: That's better because I watch the telly day and night." (F5, 70-80 years, mobile in house).*

6.5.3.4 Informal Carers

The majority of participants received help from informal (unpaid) carers, all family members. Help provided ranged from daily intimate personal care, to shopping, and emotional support. The primary role of some carers, and reliance on them, was evident in several of them being present during the interview, at the participant's request.

> *F1: "And now it's down to my partner… 'cos he's had to give up work… To be my full-time carer… Aye, the only person I've got is ma partner." (F1, 50-60 years, mobile in house)*
>
> *M2: "Obviously it's, 'cos of my weight I have to have my wife do a lot of things, I mean there's a lot of things I can't do. I mean anything for washing down the way, for knees down, even getting washed my back and things, the wife has to do all that." (M2, 60-70 years, mobile in house)*

6.6 Discussion

6.6.1 Summary of key findings

People with severe obesity experience both physical and psychological struggles around care provision, due to larger body size. Critically, these difficulties - particularly around intimate care provision but also the quality-of-life impact of poor mobility - were perceived as hidden from those without larger bodies, particularly care providers. The attendant shame created barriers in accessing appropriate care, resulting in unmet need. Findings demonstrate the negative impact of severe obesity on quality of life and mood, as participants felt stuck in their life situation, with limited hope for improvement. This was intensified for those who were bed bound, with lack of equipment or staff capability severely impacting their quality of life. There were disparate experiences of explicit weight bias. More pervasive was implicit weight bias, with care providers unprepared to provide the same quality of care to people with larger bodies as to those without. Some participants used avoidance and denial to manage internalised weight bias, contributing to social isolation.

6.6.2 Comparison with existing literature

People living with severe obesity may experience their bodies as “other”, outside of cultural norms (Haga et al., 2020, Murray, 2005), particularly the dominant biomedical discourse (Warin and Gunson, 2013, Murray, 2007, Shea and Gagnon, 2015). This “other”-ness contributes to the hidden nature of the struggles of living with severe obesity, or as fat studies scholars articulate, a fat body. This hidden, unspoken nature of the fat body has been variously described as “tacit bodily knowledge” by the medical gaze (Murray, 2007), “silence about fatness” by researchers (Warin and Gunson, 2013) or a “tactful blindness” by clinicians (Hales et al., 2016). The hiddenness serves to help cope with the social awkwardness of a larger body, both its marginalisation and hypervisibility, “saving face” for both the individual and the onlooker (Hales et al., 2016, Shea and Gagnon, 2015). By contrast, fat activists seek to “out” the fat body, by consciously speaking about it, to make it visible, renegotiating its acceptability, although this can be challenging (Murray, 2005). Such a broad spectrum of views about the larger body help to explain why the struggles of living with a larger body remain hidden, difficult to articulate.

A further element is the type of care that participants struggled with, involving bodily functions of elimination and care of sexual organs, which adults normally perform independently. To need assistance with such functions is generally stigmatising and shameful (Ostaszkiewicz et al., 2016). To do so due to larger body size, commonly seen as under the individual’s control, and attributed to laziness, loss of self-control and gluttony (Stoll, 2019, Puhl and Heuer, 2009), potentially amplifies the shame, making it even harder to discuss openly (Forhan et al., 2010). Thus, from multiple angles, the literature suggests improvements are needed for enabling open, compassionate, non-stigmatising communication about the care needs of people with larger bodies (Stoll and Egner, 2021, Kanagasingam et al., 2022).

A recent systematic review and qualitative synthesis by Farrell et al. (2021) of 32 studies about lived experience of patients with obesity notes the ubiquitous and “powerful” themes around stigma, judgement, shame and blame, which were clearly evident in this study. Denial of explicit weight stigma by most participants was unexpected, differing from Pain and Wiles’ (2006) findings. Explicit weight stigma by health professionals is common, reported by 66% of adults in weight management programmes (Talumaa et al., 2022). However, it is not reported universally (Kirk et al., 2020), with potentially lower prevalence reported for non-treatment seeking populations (Kirk et al., 2020) and recent indications of reduced incidence (Kirk et al., 2022, Charlesworth and Banaji, 2022). By contrast, implicit attitudes to weight and disability appear more resistant to change (Charlesworth and Banaji, 2022). Implicit weight bias is widespread in health care professionals (Lawrence et al., 2021), being a barrier to utilisation of primary health care with lack of training, poor communication, disrespectful treatment and attribution of all health issues to excess weight, specifically identified (Alberga et al., 2019, O'Donoghue et al., 2021a). Notably, there appears scant evidence on bias in formal home care or care home settings.

The IWB articulated by participants although not quantified, appeared strong, and consistent with results from recent systematic reviews, being associated with specific elements of poor body image, body dissatisfaction, depression, anxiety and reduced quality of life (Pearl and Puhl, 2018, Emmer et al., 2020). In common with other narratives on living with obesity and IWB, participants’ misunderstandings about the causes of obesity were connected to feelings of shame and self-blame (Ramos Salas et al., 2019, Owen-Smith et al., 2014, Farrell et al., 2021). Also the sense that their bodies had little “potential for improvement” (Haga et al., 2020) and avoidance of social situations (Ramos Salas et al., 2019, Owen-Smith et al., 2014).

Similar to Pain and Wiles, who conducted interviews nearly two decades ago, we found that services struggled to cope with the mobility needs of people with larger bodies, especially in their own homes, which can be limited in terms of space and adaptability (Pain and Wiles, 2006). To our knowledge, there is little further evidence from the perspective of community service users. The closest evidence has a narrower focus on patient experience of primary care services (family doctors and nurses) by people with obesity (Brown et al., 2006, Buxton and Snethen, 2013, O'Donoghue et al., 2021b). Conversely, our outcomes are validated by a growing international evidence base regarding care providers’ struggles when providing care. Difficulties comprise accessing equipment, appropriate training, and adequate staff, across all sectors including formal home care (Schuldt et al., 2021, Lunt et al., 2022, Ellison et al., 2020) and hospital care (Dockrell and Hurley, 2020, Ewens et al., 2022, Pazsa et al., 2022) but mainly focussed on care homes (Bradway et al., 2016, Felix et al., 2009, Parkinson and Thompson, 2021, Hales et al., 2020a, Sefcik et al., 2022, Harris and Castle, 2017). Such evidence suggests that all sectors lack credible preparedness to care for people with severe obesity.

The “sense of being stuck” subtheme, encompassing both unmet physical mobility needs, but also restriction on wider opportunities, resonates with other studies where participant’s describe “putting life on hold” (Forhan et al., 2010), being in a position of waiting, just existing, rather than living what they anticipated as their “actual” life (Haga et al., 2020). Farrell et al (2021) term this as “a life limited” with physical and mental components leading to withdrawal from participation.

Similarly the observation of “intertwined complexity” echoes the “vicious cycle” concept, identified by Howard and colleagues (Howard et al., 2016). This involves incremental worsening of multiple interdependent factors such as emotional distress, physical difficulties, environmental limitations and societal views, with the interconnectedness of factors, appearing to make it hard to achieve life improvements (Howard et al., 2016).

6.6.3 Implications for policy and practice

Given increasing numbers of people living with severe obesity, with their need for community health and social care services, these findings have potential for broader application in driving service improvements aiming for equitable, compassionate and informed care.

6.6.3.1 Staff training

Calls for staff training have correctly focussed on enabling referral to weight management and reducing weight stigma (Royal College of Physicians, 2013, Pain and Wiles, 2006, Holt and Hughes, 2020, Talumaa et al., 2022). However, this study additionally identifies that care professionals need clinically-focussed training about the physical, psychological and social challenges of living with a larger body (Lunt et al., 2022). Currently, a “dearth of clinical education” (Dockrell and Hurley, 2020) leaves staff who care for people with severe obesity, ill-equipped to even have a conversation about possible difficulties with intimate self-care, providing a more sensitive “way in” for people to access support (Forhan et al., 2020). Staff need supported to develop skills to ‘meaningfully engage” with people with obesity, to ensure person-centred care outcomes (Pazsa et al., 2022, Kanagasingam et al., 2023).

6.6.3.2 Organisational preparedness

Care pathways are needed to ensure people with severe obesity receive optimal, coordinated care that enables them to live with dignity (Ells et al., 2022, Forhan et al., 2020). Currently, the physical infrastructure of care services, especially core care equipment, appears woefully inadequate. Provision lags far behind the needs of those requiring care and discriminates against people with larger bodies receiving the same standard of care as the rest of the population. Care providers need to ensure that the physical infrastructure and staff capability of care services can safely, and respectfully, accommodate people with severe obesity (Pazsa et al., 2022). This raises interesting questions about the cost-effectiveness and adaptability of people’s homes to facilitate care versus provision in suitably adapted residential facilities.

6.6.3.3 Weight management intervention

Participants generally wanted to take action to improve their quality of life, to have hope for achieving (or maintaining) independence. Weight management treatment needs to be person-centred, individualised and holistic (Ells et al., 2022, Johnstone et al., 2020, Campbell-Scherer et al., 2020), including negotiated wider health outcomes that are meaningful for people (Ervin et al., 2020). These comprise non-weight related goals, such as sleep quality, functional mobility, managing emotional distress and quality of life (Haga et al., 2020, Ueland et al., 2019). Additionally, people may need help to deal with IWB before they are able to engage with weight management services (Ramos Salas et al., 2019, Verhaak et al., 2022, Talumaa et al., 2022).

6.6.4 Suggestions for future research

Study findings highlight multiple areas for future research. Lived experience of community care services from the perspective of people with obesity is missing (Harris and Castle, 2017, Forhan et al., 2020). Evidence regarding the development of accessible and effective weight management services for people who are housebound is needed (Holt and Hughes, 2020) and their impact on ability to perform ADLs (Ervin et al., 2020). The role and experience of informal carers in helping people with severe obesity manage day to day is unstudied (Beitz, 2015). Currently, there appears to be no research regarding weight bias in long-term care settings.

6.6.5 Strengths and limitations

This study documents a highly stigmatised, “seldom heard” population, including people who are housebound. It comes from the novel perspective of people with severe obesity who are needing help from wider services to manage at home. The pragmatic operational approach adopted to data collection due to the Covid-19 context paradoxically has both strengths and weaknesses. The clear identification as a district nurse, demonstrating familiarity with the context of care was a potential strength, enabling participants to feel safe candidly discussing intimate care needs. This may have differed with a non-nurse investigator, unfamiliar with the tacit knowledge of the “dirty work” involved in the care of bodies (Ostaszkiewicz et al., 2016). Previous work has shown interviewees have stronger preconceptions about a health professional interviewer, responding with more candid health-related responses than to a sociological “researcher” (Richards and Emslie, 2000). Consequently, the authors have tried to transparently contextualise the study, aware of the tensions of doing qualitative research about larger bodies, aiming to hold the perspective of an informed, empathic health professional (Marn and Wolgemurth, 2021, Warin and Gunson, 2013). Equally, the strong professional identification may have inhibited negative service feedback from participants.

6.7 Conclusion

Participants experienced unmet physical and psychological care needs associated with their larger bodies, leading to poor quality of care and life. Given rising prevalence, changes to services are required. Specific recommendations include staff training about needs of people with severe obesity, ensuring the physical infrastructure of care services can safely accommodate people with severe obesity and improving access to effective weight management treatments with acknowledgement of the critical role of IWB for individuals.

Chapter 7 General Discussion

7.1 Overview

This study has sought to better characterise the community dwelling population with severe obesity who use community health and social care services. Since this study began in 2016, there have been significant developments in the wider context and evidence base related to severe obesity. Particularly relevant has been the increased focus on social care utilisation, the lived experience of individuals with severe obesity, the role of weight bias, and the emergence of more effective obesity medications in GLP-1 agonists. This chapter will discuss the implications of the study's findings in the context of these developments and will make recommendations for practice and research.

7.2 "Missing data tell a story precisely due to its missingness."

Research questions 1 and 2 – concerning the number of people with BMI ≥40 kg/m^2 using health and care services, housebound and in care – are about the size of a population identified as having specific needs. Chapter 1 highlighted the degree of missing data due to the documented shortcomings with local GP data. Chapter 2 highlighted the lack of data at an international level (Williamson et al., 2020). Better mapping and characterisation of the population with BMI ≥40 kg/m^2 globally is required to enable study of causation, planning of care (including weight management treatments), and improved economic costing of treatment. Chapter 3 detailed the complexities involved in linking routine data across sectors (Williamson et al., 2022c), meaning that robust answers to research questions 1 and 2 are currently unfeasible.

Despite this, services readily identified 115 adults living with BMI ≥40 kg/m^2 and receiving community services (other than Weight Management) ((Williamson et al., 2022a, Supplementary Information) presented in Appendix 2, Table 3). Housebound individuals made up 80% of participants, with the majority (56%) <65 years old. For context, the local area[2] sampled had a total population of 93,150, adult population (16 years and over) of 75,061 (National Records of

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[2] Deliberately not named to protect participants' confidentiality.

Scotland, 2021b). Local area population age demographics were broadly similar to the general Scottish population, though slightly younger. The local area had a median age of 41.6 years compared with 42.1 years for the general Scottish population; probably explained by under 16 years olds comprising 19% of the local population versus 17% at national level; locally 63% of adults were of working age (16-64 years) compared with 65% nationally; the proportion of adults of pensionable age were the same locally and nationally at 18% (National Records of Scotland, 2021b). The local area comprised 115 data zones ranked using the Scottish Index of Multiple Deprivation: ten data zones were in the 20% most deprived, 17 in the 20% least deprived (Scottish Government, 2020c).

The use of routine data in health and social care research can present as many questions as it solves, particularly around poor recording of variables of interest. Accurate recording, coding and linkage of data is required to fully realise the potential of health and social care records to help evidence care needs. Understanding how factors such as gender, race, SES and presence of informal carers impact need for care, are hindered by poor population data. Issues of widening health inequalities may also be obscured (Finch et al., 2023).

Currently, the population with severe obesity is receiving care that is largely unevidenced partly due to the problem with getting robust data on this hard to access population. Increasing prevalence (NHS Digital, 2020b, Scottish Government, 2018b) is feeding through to care providers in the health and social care sector, with growing demand for care services gradually being documented (Schuldt et al., 2021, Zhang et al., 2019a, Local Government Association, 2020, Parkinson and Thompson, 2021, Learner, 2014). However, the lack of robust data, particularly regarding community health and social care services, makes rising demand hard to evidence to policy makers and senior care managers (Gousia et al., 2019). Subsequently, this makes it hard to justify changes to service provision, especially expensive ones such as building specialist facilities (Learner, 2014), or retrofitting buildings (Dutta et al., 2018), or stocking specialised equipment (Dockrell and Hurley, 2020), contributing to the population with severe obesity remaining underserved.

Parkinson and Thompson astutely observe:

> *"In the UK, health and social care policy continues to remain resolutely focussed on the health risks associated with non-obese older people and their weight loss" (Parkinson and Thompson, 2021, p7).*

Ambrose et al (2013) noted a focus on undernutrition in clinical services, with the Malnutrition Universal Screening Tool (MUST) used to identify malnourished patients to ensure targeted intervention. They observed that the BMI component could easily be used to potentially identify people with obesity, triggering further review, but that this did not happen (Ambrose et al., 2013). Better characterisation of the population with BMI ≥ 40 kg/m^2 is required to improve organisational and societal support for this population.

The practical challenges of gaining accurate anthropometric measures for people with severe obesity are little documented, but as Chapter 4 demonstrates, undoubtedly contribute to poor data recording (Williamson et al., 2022b). The question is, to what degree? Such challenges exemplify how care of people with severe obesity differs from care of people without obesity, illustrating the need for specialist equipment to accommodate people with larger bodies for relatively routine care processes. This study demonstrates the need for data-driven science to be informed by real-world insights (Ells et al., 2022), underlining the benefit of front-line practitioners being research active.

7.3 Excluded service utilisation and costs

Study outcomes presented in Chapter 5 clearly demonstrated that community health and social care costs for people with severe obesity can be significant and recurring over a long period, particularly those costs borne by local authorities in the UK (Williamson et al., 2022a). Hence, economic costings of obesity or cost effectiveness studies of weight management treatments that exclude these costs are materially incomplete. Whilst a focus on weight management for treating obesity is essential, so also is care of those not accessing treatment. This is especially true for those with severe obesity and disability, who can have complex care needs.

Total annual care costs for all the individuals presented in Table 5.4 were £664,860 (base case) (lower estimate £561,558; upper estimate £768,162). Long-term care costs (£317,802 covering just 12 participants) and community health costs (£85,296 including all participants) formed the majority of these. Notably, these were annually recurring costs rather than episodic as for OT costs, and were likely underestimated because of the Covid-19 pandemic. Combined one-off costs for equipment (£114,637) and adaptations (£134,194) totalled £248,831.

Translating these costs to a population level obviously requires caution given the lack of robust data on prevalence. However, some order of magnitude is helpful. Chapter 5 estimates a BMI ≥40 kg/m^2 prevalence of 4,500 adults per 100,000 adults for the local area. If 2.5% of these people (n=113) used community health and care services, at the mean cost per participant of £26,594 (Table 5.4), the estimated annual total care costs for the local area would be £2,253,842. Broadening this out to the wider NHS Lothian board area with a total adult population of 760,308, estimated total annual care costs were £22,838,927. Given this study readily identified 115 adults through non-exhaustive identification and with known data deficits for community services, the 2.5% figure appears conservative. Increasing the number of people with BMI ≥40 kg/m^2 using community health and care services to 5% (225 people), the estimated annual total care cost for the local area would be £4,487,738, with £45,475,740 estimated annual care costs for the NHS Lothian board area. Whilst anywhere between 2.5–5% seems plausible, 225 people is likely a high estimate, feasibly making the most appropriate figure for policy makers and service providers 3.75% - equating to 169 people. Applying 3.75% would give total annual local area costs of £3,370,790 and NHS Lothian board area costs of £34,157,334. Using the 3.75% figure, one off total equipment costs for the local area would be £581,249, with adaptations £680,394, making the combined figure for equipment and adaptations £1,261,543. At NHS Lothian board level, these figures increase to £5,888,974 for equipment, £6,894,659 for adaptations and £12,783,633 for both combined.

Recent years have seen a growing international evidence base documenting challenges with care provision for people with severe obesity in hospital

(Dockrell and Hurley, 2020, Pazsa et al., 2022, Hitch et al., 2020, Fusco et al., 2021), and in care homes (Parkinson and Thompson, 2021, Sefcik et al., 2022, Hales et al., 2020a, Zhang et al., 2019a, Harris et al., 2018). Yet, care provision at home and services involved remain under represented (Schuldt et al., 2021), potentially because care happens “behind closed doors”, so is largely invisible to the outside world (The King’s Fund, 2016).

Presently, the impact of obesity on social care is insufficiently documented and poorly understood, despite being potentially extensive (Gousia et al., 2019, Obesity Action Scotland, 2019). Most population studies show increasing BMI is associated with functional limitations and need for care (Harris et al., 2018). However, some do not (Amankwaa et al., 2022), with potential for divergence dependent on setting and timing of obesity onset during the life course (Harris and Castle, 2017). Future developments depend on social care data analytics being prioritised by researchers and commissioners (Scottish Government, 2022a), so that improved research can promote better planning (Nizalova et al., 2018, Local Government Association, 2020). Examples of successful linkage of health and social care data are scant, limited by age (Henderson et al., 2020) and geographical area (Shand et al., 2020).

Wider population studies using cohorts matched for sex, age, race, SES and chronic disease are needed. Given that 56% of study participants were <65 years of age, with other evidence supporting need for care amongst younger adults (Sefcik et al., 2022, Harris et al., 2018), these studies should include all ages of adults.

7.4 Interdisciplinary care

Chapter 5 delineates the different services providing care, highlighting that care of people with severe obesity is cross-sectoral and interdisciplinary (Nowicki et al., 2009, Williamson et al., 2022a). Contrary to how care services are generally organised, it does not “belong” to any single profession, or disease-specific specialism, or body part specialty. Outside of weight management services, it appears an orphan area, in short “everyone’s issue and no one’s issue”. Combined with being a marginalised population, this perhaps contributes to care of people with severe obesity being a poorly recognised area of research and practice.

The interdisciplinary nature of care presents huge challenges in both developing services for and researching this population, as there is no single point of coordination or care specialism that takes ownership or the lead in care provision (Gray et al., 2022). Different services “own” their specific part, for example, bariatric surgery, weight management, manual handling, tissue viability, community equipment, and social care, with potential intersections of multiple professions including GPs, nurses, OTs, physios, carers and ambulance staff. Consequently, the siloed working of many health systems (European Alliance for Value in Health, 2020) works against holistic, person-centred care for this population. For individuals to receive holistic, person-centred care, the wider care needs of people with severe obesity need addressed across disciplines and sectors (Ells et al., 2022, Forhan et al., 2020, Kanagasingam et al., 2023).

7.5 Care system preparedness

This study has provided evidence that research is not keeping up with current health and social care practice. Since the early 2000s, reports have highlighted poor service provision for this population (Lapane and Resnik, 2006, Pain and Wiles, 2006). Historically these were perhaps understandable given the steep rise in prevalence of severe obesity since the mid-1990s. However, findings that care services remain systematically unprepared, despite increasing prevalence, are concerning.

The implicit bias identified in Chapter 6 evidences the pervasive and structurally unprepared nature of the wider care system, to provide the same quality of care to people with severe obesity, as to those without. Services are physically unprepared with lack of appropriate equipment, such as hoists, scales and seats, lack of widened doors, and diagnostic scanners not large enough. Such environmental barriers mean care is often reactive, poor quality and unsafe, for both individuals and staff (Sefcik et al., 2022, Cowley and Leggett, 2011, Nowicki et al., 2009), promoting feelings of marginalisation for individuals (Ellison et al., 2020).

The Equality Act 2010 does not treat body size or obesity itself as a protected characteristic (Government Equalities Office, 2011b). However, the Equality Duty does treat disability as a protected characteristic, extending the legal protection to access to services. Disability is broadly defined as:

> *"a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities" (Government Equalities Office, 2011a, p4).*

This legislation also includes discrimination arising from disability, whereby people are treated unfavourably because of something *connected with* their disability, not just the disability itself. Thus, significant physical or mental health long-term conditions related to obesity could be judged a disability (Brown et al., 2022), with service providers expected to make "reasonable adjustments", including "reasonable alternatives" to care (Government Equalities Office, 2011b). Equity of care for people with severe obesity needs greater recognition by health and social care providers if providers are to meet their duties under the Equality Act (Government Equalities Office, 2011b).

Frequently, providers appear unaware of their legal responsibilities (Agaronnik et al., 2019), or neglectful of their professional responsibilities under the relevant professionals' Code of Conduct to "do no harm and treat people with dignity and respect" (Russell and Carryer, 2013). This is particularly relevant given recent findings of weight bias potentially contributing to the aetiology of obesity (Prunty et al., 2023), whilst being prevalent amongst health professionals (Puhl et al., 2021).

Currently, a "one size fits all" approach to the general population dominates, with the specific needs of this population not considered by planners (Gray et al., 2022). Effective planning and preparation of new care facilities is needed now, rather than as a crisis intervention, when individuals present for care (Feeley, 2021). Environmental adaptations are expensive in time and money, particularly when made retrospectively (Dutta et al., 2018). Health and social care sectors need to review and adapt wider provision for people living with severe obesity, aiming for equitable provision of safe, effective and person-centred care (Ells et al., 2022).

7.6 Staff training and support

Chapter 6 also demonstrated that care providers lacked awareness about the hidden struggles of living with severe obesity. Staff training has been repeatedly identified as a barrier to effective provision across care sectors (Dockrell and Hurley, 2020, Sefcik et al., 2022, Parkinson and Thompson, 2021) and multiple professions (Lumley et al., 2015, Lunt et al., 2022). Currently, the evidence base focuses on obesity care competencies for specialist obesity care providers (Capehorn et al., 2022). However, as previously noted, many people with severe obesity do not access specialist weight management services. Much of the care of people with severe obesity is, therefore, undertaken by non-weight management professionals as part of wider services (Nowicki et al., 2009). Such professionals generally have minimal training about severe obesity and weight management (Royal College of Physicians, 2013, Jackson Leach et al., 2020, Howes et al., 2021). Hence, there is a need for a more elementary level of training for generalist staff (Holt and Hughes, 2020), to help inform beliefs and practices.

Multiple studies report staff recognising their own knowledge deficit and rating need for training about obesity as a high priority for improving care (Parkinson and Thompson, 2021, Dockrell and Hurley, 2020, Lumley et al., 2015). Curiously, a dearth of generalist training appears available (Royal College of Physicians, 2013), together with a lack of strategic recognition by wider care organisations regarding this deficit (Parkinson and Thompson, 2021, Lumley et al., 2015). This may be symptomatic of severe obesity being an orphan area, thus having no one to “champion” it at board level or be responsible for training in practice. Staff training appears a key place to start improving quality of care, potentially simultaneously increasing staff job satisfaction. Training recommendations frequently focus on the essential areas of reducing bias and weight management (Campbell-Scherer et al., 2020), but should include wider knowledge about the experience of living with obesity and causes of obesity, equipping staff to “meaningfully engage” with people with obesity (Pazsa et al., 2022). Suggested areas for inclusion are outlined under Recommendations for practice.

Staff training could also target the needs of specific professional groups. For example, training around continence and skin integrity for staff providing personal care; basic nutritional education for staff involved in meal provision; and anticipatory care (including evacuation planning and medication dosage) for community nurses and GPs. To the author's knowledge, minimal evidence base exists around in-practice training, requiring evaluation of such interventions.

Currently most staff and individuals have no recourse to specialist support or advice, as they do for other care needs or disease groups, such as specialist nurses for cancer care, multiple sclerosis or dementia. Imhagen et al (Imhagen et al., 2022) suggest the usefulness of such a role in primary health care to support and coordinate care. Pazsa describes a multidisciplinary Bariatric Assessment Team, as a service innovation at a hospital in Melbourne, Australia, who provide

> *"recommendations and facilitate(s) education around equipment provision, bed allocation, manual handling, skin integrity, referrals and discharge planning"* (Pazsa et al., 2022, p2).

Whilst the evidence is lacking, particularly for community care, given the increased population with severe obesity, the commonality of problems faced by staff risks "reinventing the wheel" across organisations and sectors. Given poor evidence, enabling co-ordination and sharing of what works and what does not, appears valuable, also informing future research direction. Currently in the UK, to the author's knowledge, there are no facilities, resources or network to do this. Specialist support for staff, particularly as the evidence base develops, has potential to benefit staff effectiveness, patient experience and organisational efficiency (Nowicki et al., 2009).

7.7 Whole organisation approach

The implicit weight bias evidenced in Chapter 6, together with the lack of organisational preparedness, suggest a lack of systems and policy to support staff in delivering safe, effective, person-centred care (Pearl and Hopkins, 2022). An implementation gap exists between the policy intent of people being able to access person-centred care (The Health Foundation, 2016, NHS Lothian, 2018) and the experience of care in the real-world (Parkinson and Thompson, 2021, Cardel et al., 2022). Individual staff may be responding as best they can, but are stuck in the middle between rising numbers of people presenting for care and organisations that seemingly do not recognise or strategically plan for care of this population (Lumley et al., 2015, Parkinson and Thompson, 2021). The qualitative outcome of “intertwined complexity” in Chapter 6 highlights this point.

Even where participants felt that they did not experience explicit stigma, they frequently received the message that care was more difficult or complex due to their weight or size. This reflects well-documented reports that care provision for someone with severe obesity is often physically and mentally more effortful, requiring more staff, more time and more space than for somebody without obesity (Ewens et al., 2022, Harris and Castle, 2017, Hitch et al., 2020, Parkinson and Thompson, 2021, Felix et al., 2009, Lumley et al., 2015, Kosar et al., 2018, Schuldt et al., 2021, Shea and Gagnon, 2015). Some care procedures, like hoisting out of bed or catheterisation, can require a non-standard approach (Alnadhari et al., 2018). Given this complexity and physical intensity of care provision, there is evidence that staff deliver care differently, “clumping” care tasks together to ensure that there are enough staff available to assist (Shea and Gagnon, 2015). Staff report doing this to protect their own safety in terms of physical strain, and use their time optimally, but equally are aware that it represents a departure from standard care and that people with severe obesity are entitled to the same quality of care as others (Shea and Gagnon, 2015).

There is concern amongst both staff and researchers that this “intertwined complexity”, with associated resource and quality of care issues are not understood at a higher organisational or policy level by senior stakeholders (senior managers and policy makers) (Parkinson and Thompson, 2021, Lumley et al., 2015). Consequently, people with severe obesity receive little attention, forgoing a coordinated or even informed approach, as shown in Chapter 6. Staff need to be appropriately resourced to provide effective care (Lumley et al., 2015, Parkinson and Thompson, 2021). Inadequate resourcing may not only compromise safety and quality but may also feed negative perceptions by care professionals of caring for people with severe obesity (Hitch et al., 2020), potentially contributing to weight bias. As Harris and Castle (2017) observe, little is known about the impact of caring for high numbers of people with obesity on recruitment and retention of staff.

Feedback from front-line practitioners suggests that many service managers act locally and independently of the wider organisation (Dockrell and Hurley, 2020). Given the multiple service budgets currently contributing to care, evidenced in Chapter 5, lack of an organisational approach works against ensuring coordinated use of resources, or good outcomes for individuals or organisations (European Alliance for Value in Health, 2020). Several examples of this arose from study data. One example is rise-recline chairs, frequently used by people with severe obesity instead of a bed - due to inability to lie flat, but also helping with postural management of lower limb oedema, whilst facilitating independent mobility for people. These have commonly been core items of community equipment provision but have increasingly been withdrawn. Such a move seems contrary to the stated aim of reducing avoidable hospital admissions and using equipment to reduce need for formal care (The Health Foundation, 2016). A further example is lack of rehabilitation facilities that can accommodate people with severe obesity, particularly when they have reduced mobility, helping them to remobilise. This can result in both inappropriate & prolonged hospitalisation, chronic poor functionality and intense and long-term service provision by health and social care services, as seen in Chapter 5.

Care home providers in the UK and the US report that the “intertwined complexity” in providing care for people with severe obesity leads to them turning people away due to lack of facilities, staff and training (Parkinson and Thompson, 2021, Hales et al., 2020a, Sefcik et al., 2022, Harris and Castle, 2017, Learner, 2014, Felix et al., 2016). However, these people still need care, meaning that they are more likely than people without obesity to be cared for in poorer quality facilities (Zhang et al., 2016), or endure inappropriate stays in hospital (Schafer and Ferraro, 2007) or receive care in unsuitable home environments, leading to poorer quality of life as outlined in Chapter 6.

Furthermore, current trends in the UK and US regarding social care favour domiciliary home provision rather than institutionalised care (Schuldt et al., 2021, Parkinson and Thompson, 2021). Paradoxically, staffing, space and equipment provision may be even more inadequate and limited in the uncontrolled home environment. Equally, the complexities and cost-effectiveness of adapting people's homes appears unrecognised by stakeholders (Schuldt et al., 2021).

Given this population is highly stigmatised and marginalised, complex to care for, and needful of resources in terms of specialist equipment and staff (Harris et al., 2018), it is not uncommon for staff, including clinical leaders, to seek to avoid providing care for this population (Shea and Gagnon, 2015, Hitch et al., 2020). Effective policy and care pathway development is urgently needed at a whole organisation level and ideally cross-sector. A strategic and planned organisational approach to policies and planning has been shown to promote more informed oversight of resource usage and care delivery, with improvements in quality of care and safety of care (Nowicki et al., 2009)

7.7.1 Bias in organisational response

A further factor impacting poor organisational response to the population with severe obesity is the implicit bias identified in Chapter 6 (Gray et al., 2022). The burgeoning evidence on weight bias has largely focussed on experience in healthcare (Puhl et al., 2021), or people with obesity (Ramos Salas et al., 2019), or the general population (Charlesworth and Banaji, 2022). To the author's knowledge, little work exists on institutional stakeholders, such as senior managers and policy makers, who influence strategic service decisions. Yet these individuals, with key roles in resourcing and priority setting for care services, are as open to weight bias as anyone else, with evidence showing that implicit attitudes in the general population have not changed in recent years (Charlesworth and Banaji, 2022). A study of clinical leaders and managers in an Australian metropolitan public hospital recognised care of people with obesity as needing of improvement, whilst also perceiving the population as problematic, with examples of complacency around low standards and "othering" where people with obesity are seen as a separate, stereotyped group (Hitch et al., 2020).

Lack of quantitative data can easily be cited as a reason for poor organisational response. Yet, as the anthropometric measures detailed in Chapter 3 show, this is a circular argument. Lack of appropriate equipment contributes to the very problem of poor data, inherently demonstrating the structural and institutional nature of weight bias in care systems. There are similarities to the institutional racism identified in the Metropolitan Police in 1999, where processes did not necessarily set out to discriminate, but discrimination occurred because of uncritical practices and failure to consider the consequences of actions on the affected people (MacPherson, 1999). The report defines institutional racism as

> *“The collective failure of an organisation to provide an appropriate and professional service to people because of their race. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people,”(MacPherson, 1999, section 6.34).*

One could substitute ‘size’ for ‘race’ in the above statement to reflect the implicit weight bias prevalent in care organisations, as evidenced in qualitative outcomes. Previously, where deficits were identified around data recording of diverse population needs, senior leaders have acted to facilitate solutions (Davidson et al., 2021). The same is needed for weight bias if institutions are to plan for care provision that includes people with severe obesity.

Multiple changes in the rapidly advancing evidence base around excess weight take time to filter into real-world practice (ConscienHealth, 2023). People working outside of the specialisms of weight management or obesity studies may be unaware that; excess weight unequally impacts people already subject to systemic disparities, such as gender, race and socioeconomic status (Public Health Scotland, 2022, Harris and Castle, 2017); and weight bias also appears to further contribute to obesity (Tomiyama et al., 2018), avoidance of health care utilisation (Alberga et al., 2019), and marginalisation (Howard et al., 2016). They may also be unaware of recent developments shifting away from viewing obesity as a lifestyle choice for which individuals are blamed, being seen as unworthy of resources, to treating it as a disease. This marks a major transition from where services have denied “access to care on the presumption that people should be able to control their weight” (Pearl and Hopkins, 2022), to person-centred obesity care (Ells et al., 2022).

Researchers and specialists need to seek to influence, advocate and educate others within their spheres of practice promoting empathy, equality of access and improved understanding of people living with severe obesity, to counter prejudice in delivery of care (Howick and Rees, 2017, Lunt et al., 2022). An important aspect of such advocacy is prioritising the participation of people with lived experience of severe obesity in service design and research (Ells et al., 2022, Farrell et al., 2021).

7.8 Access to effective weight management treatment

Chapter 5 highlights the small numbers in this study recorded as having accessed weight management, mirroring wider evidence that many people with severe obesity have no record of weight management treatment (Booth et al., 2015). Current evidence shows services are seeing significant demand from people with severe obesity, who accounted for over half of adults referred in Scotland from October 2019 to September 2021 (Public Health Scotland, 2022). As identified in Chapters 1 and 2, without better population data on BMI ≥40 kg/m^2, it is difficult to know what proportion of the total population with severe obesity this represents.

Chapter 6 demonstrates the cost of severe obesity in poor quality of life for individuals, and Chapter 5 the costs to the resources and focus of care organisations, and ultimately to wider society. Prevention of excess weight is inherently better than treatment. Treatment of excess weight, with safe, sustained weight loss offers potential for improvement with multiple comorbidities and consequences of obesity - physical, psychological, social and functional (Sattar et al., 2023). Weight management services should, therefore, be available to all who want them (Cardel et al., 2022); but access to, and engagement with, these services needs optimised for people with severe obesity (Robertson et al., 2022). Current evidence suggests helping individuals reduce internalised weight bias by promoting a wider understanding of obesity, facilitates both engagement with interventions and improved quality of life (Verhaak et al., 2022, Ramos Salas et al., 2019, Grannell et al., 2021).

Cross-sectional and longitudinal epidemiological studies show excess weight linked to functional decline (An and Shi, 2015, Cheng et al., 2017, Hajek and

Konig, 2017). For the population with functional limitations associated with higher levels of obesity, effective weight management interventions have the potential to reduce the impact of weight on activities of daily living, such as mobility (Ervin et al., 2020). Subsequent quality of life gains may thus be greater for people with severe obesity (Buckell et al., 2021), possibly realising reduced need for care (Gousia et al., 2019). However, successful intervention studies showing slowing or reversal of functional limitations appear to be lacking (Serra-Prat et al., 2021). Therefore, a key area for future research is the ability of weight management interventions to prevent or slow functional limitations associated with obesity.

A related research question would be the optimal timing of weight management intervention to potentially prevent or slow people progressing along any continuum of escalating dependency. In this study, a subgroup of seven participants had costs ≤£6000, solely related to use of community health services, largely district nursing. Analysis of study cost data could interpret escalating dependency as people being referred to OTs for equipment and adaptations to assist managing at home, before progressing to needing social care support as functional limitations increase. Finally, some people may progress to the highest intensity of support in care homes. When might weight management interventions be best placed to improve functional limitations and quality of life?

Interventions should be multidisciplinary, personalised and take a holistic health-focussed, rather than weight-focussed approach, seeking to address the root causes of weight gain (Campbell-Scherer et al., 2020, Cardel et al., 2022). Interventions should have multiple components, including the offer of physical activity, which is associated with reduced disability, potentially having a protective effect against functional disability (Keramat et al., 2021, Nizalova et al., 2018). Where standard dietary and lifestyle behavioural strategies are ineffective, they may be supplemented with appropriate anti-obesity medications (Campbell-Scherer et al., 2020), including new agents semaglutide and liraglutide (Grunvald et al., 2022) or TDR (McCombie et al., 2019). The option of bariatric surgery should be available and explored where relevant (National Institute for Health and Care Excellence, 2014).

Group interventions can be more effective (Street and Avenell, 2022), but there should be a choice of individual delivery, as some participants can find a group setting, particularly for physical activity, anxiety provoking, reducing engagement (Howard et al., 2016). For people who have functional mobility problems, or are housebound the rise of digital delivery models, catalysed by the Covid-19 pandemic, potentially offers improved access to care (Hinchliffe et al., 2022). The optimal nature of such approaches, including when hybrid or in-person visits may be necessary, plus consideration of digital exclusion and low literacy, requires further work (Morgan-Bathke et al., 2022), as these represent underserved groups (Robertson et al., 2022, Holt and Hughes, 2020). Where community health and social care staff are providing input (for example, social carers, district nurses, OTs), the opportunity for multidisciplinary collaboration to support behaviour change should be explored (Holt and Hughes, 2020).

7.9 Recommendations for practice

Recommendations for practice (7.9) and research (7.10), derived from study findings, are now presented.

7.9.1 Improved recording of anthropometric measures

1. Improve recording of measured height/weight/BMI in health and social care to promote population studies using real-world data and safe care. Where measures cannot be taken, self-report should be used, clearly documented as such. Adopt a universal approach to taking measures, so that people at extremes of the body size scale do not feel targeted or stigmatised.

2. All care services, including social care, should share responsibility for measures. Social care recording systems should have a dedicated field for recording weight and BMI.

3. Portable bariatric, wheelchair, and bed weighing scales should be routinely available to community practitioners.

7.9.2 Organisational preparedness for people with larger bodies

7.9.2.1 Develop whole systems care:

1. High-level organisational championing care of people with severe obesity within health services, so that needs are recognised, with responses owned and planned for by the organisation.

2. A specific focus on where quality and safety of care is not meeting the Equality Act 2010, to ensure people with severe obesity have the same access to care as those without obesity.

7.9.2.2 Develop specialist bariatric care role:

1. To resource and support staff in care provision.

2. To advocate and educate others within their spheres of practice promoting empathy, equality of access and improved understanding of people living with severe obesity, to counter prejudice in delivery of care.

7.9.2.3 Develop care pathways:

To promote safe, effective (evidence-based where possible) person-centred care:

1. Focussed on health-outcomes, including quality of life, function, participation, and reducing internalised weight bias.

2. Aiming to reduce inequalities in provision, regarding equipment, staff training and access to treatment.

3. To improve coordination between multiple services and sectors, focussed on prevention of admission, promoting discharge, and health outcomes.

4. To include anticipatory care.

7.9.2.4 Develop staff training:

1. For general staff (for example, bite size (1-2 hour)/half day/full day training), supporting them to develop skills in care of people with obesity, including:

    a. Weight bias; explicit weight stigma, internalised and implicit weight bias and their impact, importance of language, environmental considerations.

    b. The wider causes of (severe) obesity and their complexity.

    c. The impact on prevalence of sex, age, race and SES.

    d. Common comorbidities, including functional limitations such as mobility, urinary incontinence and skin changes.

    e. How changes in function affect participation in ADLs, including impact on psychological well-being, quality of life and strategies for coping.

    f. Weight management treatments, including behavioural, medication, surgery, and using a health-focussed approach.

    g. Person-centred assessment for obesity and how to refer.

    h. When and what anticipatory care may be suitable.

    i. Liaison with partners of Scottish Ambulance Service, Scottish Fire Service for evacuation planning and emergency preparedness.

7.9.3 Weight management interventions

Effective weight management interventions for people with severe obesity should include:

1. Support to tackle internalised weight bias, to facilitate engagement with treatment.
2. A person-centred approach, with jointly agreed health-focussed goals, where appropriate to include functional goals, including mobility or personal care.
3. Provision for people who are housebound or with mobility difficulties, potentially using digital delivery options, with or without in-person intervention.
4. A multidisciplinary approach - where community health and social care providers (carers, district nurses, OTs) are involved they could be potential collaborators with weight management services, reinforcing & supporting behaviour changes, and optimising care.
5. Opportunity for individualised physical activity, including chair-based activity.
6. Access to options of anti-obesity medications, TDR, and bariatric surgery as clinically relevant and assessed as suitable.

7.10 Recommendations for research

7.10.1 Improved data collection and recording for population health surveys

1. Review anthropometric data collection methods for population health surveys to improve accessibility for people with BMI ≥40 kg/m^2:
    a. As a minimum, include use of bariatric portable stand-on scales, with consideration of availability of portable wheelchair weighing scales at a locality level.
    b. Explore alternative measures of height for the population with BMI ≥40 kg/m^2 who are unable to use stadiometers, e.g. validity of ulna

length, or using more pragmatic measures - such as height measured against a door post.

2. Increased reporting of BMI ≥40 kg/m^2, particularly where it has been measured but not reportedly separately from BMI ≥30 kg/m^2. Further disaggregation of BMI ≥40 kg/m^2 subset into higher BMI groups 50/60/70 kg/m$^{2.}$

3. The definition of BIVs and use of upper thresholds for weight and BMI in research studies requires re-examination in view of the documented shift in population distribution towards heavier BMIs.

7.10.2 Wider population studies

1. Conduct wider population studies that:

    a. span all ages of adults.

    b. use a matched case-control method.

    c. look at wider data sources for community, mental health, primary care and social care data, and include the care home population.

    d. utilise cross-sector data linkage techniques to link hospital, community, mental health, primary care and social care data.

2. The wider costs of community health and social care should be included in health economic analysis of cost of illness studies for obesity and cost effectiveness of weight management treatments. Future areas of exploration include:

    a. Better characterisation of the population with BMI ≥40 kg/m^2, including age, sex, race, SES, comorbidities, how the duration and severity of obesity affects functional limitations, quality of life and the need for formal and informal care.

b. longitudinal studies to explore if age of onset of obesity affects functional limitations.

c. the role of informal carers for people with severe obesity.

d. What modes of intervention are accessible and effective for populations with functional limitations associated with obesity, some of whom may be housebound?

Interventional studies to examine:

a. Can weight management interventions slow or prevent the functional limitations associated with obesity?

If so,

   i. What are the key components of such interventions?

   ii. When would be the optimal timing of such interventions?

7.10.3 Develop research capacity of non-medical health and care research

Specific issues for consideration to improve clinical research and service evaluation include (Williamson et al., 2022c):

1. Develop further training due to the technical complexity of current data governance context.

2. Promote toolkits such as the Scottish Information Sharing Toolkit and Data Sharing Code of Practice, including standard templates for DSAs.

3. Encourage early, exploratory conversations with approvers regarding data governance aspects of study design.

4. Improve resourcing of approvers: recognising the increased workload as data governance has gained complexity, so reducing waiting times for approvals.

5. Establish clear lines of information sharing between data controllers, particularly where sharing for service benefit.

6. Develop unified submission approach to clinically-led research and service evaluations across NHS and partner organisations.

7. Promote clinical academic status in healthcare workforces, to release the full potential of routinely-collected data.

8. Facilitate collaborations with practitioners on data projects.

7.10.4 Research into staff support

Evaluate:

1. The composition and impact of:

    a. in-practice training provision,

    b. specialist support,

    c. the role of care pathways, policies and guidance on quality of care, cost, staff experience and experience of people with severe obesity.

7.10.5 Weight bias research

1. Explore prevalence, existence and impact of weight bias in senior stakeholders in care organisations/care systems (for example, senior managers and policy makers), who have decision-making powers around service development for people with obesity.

2. Explore the role of weight bias and its impact in domiciliary staff working in community (for example, home care, district nurses, OTs).

3. Explore internalised weight bias in people with obesity who are housebound.

7.10.6 Lived experience research

Explore the lived experience of:

1. People with obesity who require and use specialist equipment and adaptations in their own home, particularly barriers and facilitators to accessing equipment and impact on quality of life, need for care, and on other occupants of the dwelling.

2. Informal carers of people with severe obesity, particularly the impact on them physically, psychologically, socially and economically.

3. Health and care staff who provide care to people with obesity who are housebound, particularly district nurses, OTs, social carers, physios, podiatrists, GPs, but extending to other relevant sector staff such as paramedics and fire service staff, who can be involved in extrication.

7.11 Conclusion

> *"The role of researchers who engage in critical inquiry is to produce more nuanced ways of understanding… practice and to work toward transformation by raising awareness, educating, challenging the status quo, or identifying issues that go beyond the individual" (Shea and Gagnon, 2015, pE20).*

Whilst the study has been unable to fully answer all the research questions outlined at the start, it has succeeded in documenting a population largely absent from the evidence base. Furthermore, it has uniquely characterised the population's need for care, both in quantitative and qualitative terms. It has also illuminated the poorly documented roles of community health and social care staff, such as carers, OTs and district nurses.

The evidence presented is small scale, but robust. It definitively outlines a population needing prioritised for further research. The scale and longevity of costs presented, in under resourced areas experiencing huge service pressure, should be of interest to all aiming for efficient and effective care. Such costs need inclusion in comprehensive health economic analysis to maximise the economic rationale for access to effective obesity treatments.

Growing international evidence about care home usage by people with severe obesity, corroborates both the rationale and findings of the study. Now researchers need to engage at scale with the messy data environment of home health and community care, to understand more about how functional limitations associated with obesity impacts care delivered at home. The fundamental impact of home care delivery on the NHS is increasingly recognised, much discussed, but little researched. Obesity will play an increasing role in home care provision in the future.

Interdisciplinary evidence, policies and care pathways, supported by a whole organisation approach, are needed to improve compassionate care of people with severe obesity, with clinical leadership and training to support implementation. Understanding of weight bias, complex causes of obesity, and the resourcing of health-focussed treatments, need to be accepted by stakeholders to see improvements in quality of life for people with severe obesity.

The current costs, in terms of community care and poor quality of life for people with severe obesity, are too high to ignore any longer.

Appendices

Appendix 1

Search strategy and terms for systematic database search for scoping review

Williamson, K., Nimegeer, A., & Lean, M. (2020) Rising prevalence of BMI ≥40 kg/m^2: A high-demand epidemic needing better documentation. Obesity Reviews. 21, 4, e12986

Last search undertaken on 28th September, 2019.

Medline (Ovid) & Embase

(National health survey or national population surveillance or national prevalence or epidemiological survey).tw

(BMI or body mass index or obes*).tw

Limited to humans, (all adults (19 plus years), English language, 2016 – current, All types of publication

(Child or children or adolescents or baby). Tw records removed

Appendix 2

Published as Supporting Information for

Williamson, K. Blane, D.N., Grieve, E. & Lean, M.E.J.(2022) Overlooked and under-evidenced: Community health and long-term care service needs, utilisation, and costs incurred by people with severe obesity. Clinical Obesity, e12570, ***doi.org/10.1111/cob.12570***

1. Help at home questionnaire: p175-188
2. Micro-costing notes:p189-195
    a. Table 1: Unit costs-staff costs per hour: p189
    b. Table 2: OT/SW staff time input summary of figures used for sensitivity analysis: p192
3. Table 3: Summary demographics: Participants, non-participants and census groups: p195

Help at home for people living with a higher weight
A study exploring sources of help used by people with BMI 40+ at home, part of EXPRESSO.

Help at Home questionnaire: administered by study researcher face to face during home visit.

Introduction:

As someone who is housebound with a higher weight (BMI 40+), we are interested about your personal daily needs and what help you may need meeting them. You might receive some help from health and social care services, whilst other help may come from family, friends, volunteers, or people you pay. There are no right or wrong answers, all of this is of interest to us.

We understand that these questions cover personal, sometimes sensitive subjects: we are asking them to better understand the type of help you need, not to be intrusive or judgemental. Your response is confidential. If you would rather not answer the question, please just ask to pass to the next question.

PART A:

1. I would like to start off thinking about what help you may need day to day: Here is a list of common tasks in daily life, give Showcard A (Appendix 1) with tasks on (as listed in column 1 of table).

Thinking about the past month, starting at the top, can you tell me if you have needed help with any of these? Once we know what areas you have help in, we'll go into more detail about what kind of help.

2. Now I am going to think about *who* might help you with these tasks:
   On Showcard B, (on the back of Card A) Appendix 2 is a list of people who might help you, which I will guide you through.
   After we have worked out who helps you, I would also like to know roughly how long they spend helping you to the nearest 15 minutes, and then how often they help you with that task. We will do one task at a time.
   So if we start with getting out of bed: *cover all tasks*

   1. **Family member:** husband/ wife/partner; brother/ sister; son/ daughter; niece/ nephew; mother/ father; grandchild; including step/adopted/ in-law for all of the afore mentioned.
   2. **Friend**: someone one who is known to you & not a family member as defined above and does not receive payment for care, includes neighbours.
   3. **Local Authority carers**: care staff paid directly by the council.
   4. **Local Authority funded Care Agency**: care staff funded by the council but someone else provides the help (e.g care agency, charity worker), ie you or your family can't change the help you get without asking someone in the council.
   5. **Independent Living Fund/ Direct payments:** help funded by Independent Living Fund/ Direct payments or equivalent.
   6. **Privately arranged help**: help funded privately (e.g. by you or your family) and you or your family directly control it.

ADLs*	Help required: *Yes or No*	Who?[1]	Nº of people?	Time for each activity?[2]	Frequency of activity?[3]	How long have you been receiving help?[4]	Comments
1. Getting in or out of bed							
2. Having a bath or shower or bed bath							
3. Washing hands & face/skin care							
4. Dressing or undressing							
5. Using the toilet/pad change/catheter care							
6. Cooking							

7. Eating							
ADLs*	**Help required:** ***Yes or No***	**Who?**[1]	**Nº of people?**	**Time for each activity?**[2]	**Frequency of activity?**[3]	**How long have you been receiving help?**[4]	**Comments**
8. Taking medication							
9. Getting around indoors							
10. Other tasks: a. going out (assist with car/bus?) b. food shopping c. housework d. laundry e. paperwork f. paying bills g. obtaining medication							
11. Other help[5]:							

*As per HSE 2017 [1] Family=1, Friend=2, Local authority carers=3, Local Authority funded Care Agency=4, Help funded by Independent Living Fund or equivalent=5, Privately funded help=6, Third sector (housing association/ charity/ social enterprise)=7, Other=8, [2] To nearest 15 mins, if help covers number of tasks at one time, group codes for task together in comments & record total visit length, or ask for total time per week x[3] per day for tasks 1-9, per week for tasks 10a-f, [4] ≤ 3/6/9/12 months, <2/3/4/5/6/7/8/9/10/11/12 years, ≥12 years, [5] including supermarket delivery services, Uber eats, Deliveroo, pharmacy delivery

Thank you very much.

Part B: I am now going to move onto health & community services.

Thinking about the past year can you tell me about any help you have received from health (provided by NHS) and community care staff (provided by Council?)

As with Part A, I am interested in:

- who has provided help,
- what help they have given you,
- the time involved,
- how often it happened and
- how long you were receiving help.

I will work through a number of people who might have been involved, then we can check whether there is anyone else that we haven’t mentioned already. Does that sound ok?

Service	**Current**	**Past**	**Help required**[1]	**Length of visit?**[1]	**Frequency of activity?**[2]	**Length of involvement?**[3]	**Comments**
1. Occupational Therapist			1. Equipment 2. Housing adaptations 3. Housing 4. PoC 5. Other:				
2. District Nurse			1. Catheter 2. Skin care (including wounds) 3. Diabetic care 4. Monitoring (inc NEWS) 5. Other				Number of staff: Grade of staff: Wound: pressure trauma leg
3. Physiotherapist							Home visit?
4. Dietitian/ Weight Management (inc @ Diabetic OPD)			1. Weight management 2. Other				Home visit?
5. Podiatrist							Private or NHS?
6. GP staff[4](specify GP: nurse: HCA: NP)							

Service	Current	Past	Help required[1]	Length of visit?[1]	Frequency of activity?[2]	Length of involvement?[3]	Comments
7. Social work							
8. Continence care			1. Pads per day 2. Pads per night				Buy own pads?
Any other services[5]:							

[1] to nearest 15 mins; [2] x2 daily, daily, x3 weekly, weekly, fortnightly, monthly, 6 weekly, 8 weekly, 12 weekly; [3]≤ 3/6/9/12 months, <2/3/4/5/6/7/8/9/10/11/12 years, ≥12 years, [4] GP, Practice nurse, HCA, Nurse Practitioner; [5]Hospital at Home, Home Ventilation Team, Community Respiratory Team, Tissue Viability, Community Diabetic Nurse, Psychiatrist, Psychologist, Community Mental Health Team, Community Psychiatric Nurse, Smoking Cessation, Bowel & Bladder Specialist Nurse, NHS 24, A & E, MERRIT (Midlothian Emergency Response Team)/ Community Alarm Service, Befriending, Optician, Dentist, Home oxygen provider (e.g. BOC), Health coach, Peer support worker

Thank you very much.

We are now going to move onto think about equipment that you may have received. I will suggest equipment that you may have and you can fill in the details.

Part C: EQUIPMENT:

1. Do you currently use any aids or equipment? Yes No
2. **Mobility Aids: Yes No**
   a. Electric Hoist Electric Stand aid Manual Stand Aid (e.g. Sara Stedy)

      Gantry Hoist/ Ceiling Track (area covered / straight track or H frame)

      Turner

      Type

   b. Number of slings: Type:

   c. Zimmer Standard Bariatric

   d. Stick Crutches Standard Bariatric NHS

      Private

   e. Wheeled walkers Standard Bariatric NHS

      Private

   f. Mobility Scooter Standard Bariatric NHS

      Private

3. **Beds/ Seating**

a. Electric Bed: Standard Bariatric NHS Private

b. Pressure relieving mattress: Foam Air (e.g. Repose)

Dynamic

NHS Private

c. Bed rails Bed rail protectors:

d. Monkey pole: Trapeze Bed grab rail

e. Glide sheet(s) Glide sheet system: ETAC Immedia Wendylett

4. **Chair**

f. Rise-Recline Chair Standard Bariatric NHS

Private

g. Other chair: Standard Bariatric NHS

Private

h. Specialist chair: Standard/ Bariatric Custom: NHS Private

i. Wheelchair: electric manual Standard Bariatric NHS Private

j. Customised: Wheelchair pressure cushion

k. Pressure relieving cushion: Foam (Propad) Air (Repose) Gel (Conforming)

l. Perch stool: Standard / Bariatric

m. Bed side / chair side table Handigrab / Dressing aids

5. **Bathing equipment:** Yes No

a. Shower chair stool Bath chair: standard bariatric

b. Type: Customised

c. Toilet seat frame Commode standard

bariatric

d. Urinal bottle Catheter stand

Any other equipment:

a. Positioning wedges Foot raiser Prosthetic(s)

b. O^2 machine nebuliser CPAP / BiPAP

c. Other item(s):

Part D: Housing Adaptations:

Thinking now about your home, I am interested if you have needed any house adaptations to help you?

a. Access: Key safe Intercom Ramp

b. Hand / Grab rails Position:

c. Stairlift: Curved / straight Standard / Bariatric Private / LA supported

d. Bathroom: Wetfloor Toilet: Heavy Duty / Wash & Dry toilet

e. Floor strengthening Stair strengthening

f. Space enlarged**:** bathroom / living

g. Door widening Threshold smoothed Double doors

h. Structural survey completed? Yes no

Part E: Rehousing:

a. Current housing type: Tenure:

b. Rehousing advised (by whom?) Pending Completed

c. Reason

d. Accepted by client:

e. What have you been offered?

f. Length of time for rehousing:

g. Number of bedrooms: in previous house new house

h. Other differences in new house:

i. Further details:

Part F: Any other help not already mentioned (chemist delivery, food deliveries (e.g. carry out deliveries, Uber Eats, Deliveroo, supermarket deliveries, Wiltshire Farm Foods) Motability, blue badge, designated parking space, respite, Third Sector (Befriending, VOCAL), hairdresser, nails, massage, medical waste bins, larger waste bins

Additional Recording Space:

Statement for if participant starts to give information more suited for semi-structured interview:
So what you are telling me is the kind of thing that I am very interested in for the interview part of the study. I can’t write fast enough to get it all down now and I really want to capture it exactly in your words, which is why I plan to record it. Would it be ok to jot down some brief notes that may be helpful to remind you of this if you were to do an interview? Then we’ll carry on with the questionnaire.

SHOWCARD A:

1. Getting in or out of bed
2. Having a bath or shower or bed bath
3. Washing hands, face & body/skin care
4. Dressing or undressing
5. Using the toilet/pad change/catheter care
6. Cooking
7. Eating
8. Taking medication
9. Getting around indoors (including transferring)
10. **Other tasks:**
    a. going out
    b. food shopping
    c. housework
    d. laundry
    e. paperwork
    f. paying bills
    g. obtaining medication

SHOWCARD B:

1. Family member (including in-laws/step/adopted)
2. Friend (including neighbour)
3. Council-employed care worker
4. Agency Care worker (funded by council)
5. Personal assistant (funded by Independent Living Fund/ Direct Payments)
6. Care worker (including cleaner) (privately funded)
7. Third Sector e.g. Sheltered housing warden/manager/charity/voluntary
8. Other: *ask participant for details*

MICRO-COSTING NOTES

1. Unit costs

Appendix 2 Table 1 Unit costs: Staff costs per hour

Local authority carers	£24
Local authority commissioned care agency[a]	£17

	Band 4	Band 5	Band 6[b]	
District nurse (DN)	£30	£39	£49	
Physiotherapist (Physio)			£48	
Dietician			£48	
Podiatrist			£48	
Community Psychiatric Nurse (CPN)			£49	
Social Worker (SW)			£45	
Occupational Therapist (OT)			£45	
Consultant Psychiatrist				£116

Legend: 2019/2020 values (Curtis and Burns, 2020); [a]from The King's Fund (The King's Fund, 2021); [b]or equivalent grade if employed by local authority.

2. Grades of staff

a. District nurses costed at Band 5, as these form most of the staff group. Care is also performed by Bands 4, 6 & 7. In the United Kingdom, the role of the district nurse is generally provision of nursing care within a person's home or in care homes, rather than in clinics. It is broadly similar to home health nursing in the United States and community nursing in New Zealand.

b. Occupational therapists (OTs)/physiotherapists/podiatrists all costed at Band 6.

3. Service utilisation/dose of care calculation

a. Long-term care

Long-term care (LTC) utilisation, particularly home care packages of care (PoC) can rapidly change in intensity of provision (carer hours provided). Thus, utilisation data covered the month pre-data collection. Care at home package of care data and dates of admission to care home were verified via local authority electronic records. Additionally, out of hours (OOH) service utilisation for urgent care e.g., falls or unplanned personal care (toileting) was also verifiable, with some participants receiving a significant amount of care this way. Where appropriate a weekly mean OOH figure was calculated and added to the weekly scheduled PoC to give a representative total weekly time usage. Total hours per week were multiplied by 4.5 to give monthly figures.

For participants resident in care homes, no dose of care was calculated, as care is always available. Instead published weekly costs (Curtis and Burns, 2020) were multiplied by 4.5 to give monthly costs.

One participant, with a home care PoC had an emergency admission into care home accommodation during this month. For this participant, their home care PoC was used as the basis for utilisation and costings to avoid over-inflating annual figures, given it was unknown if care home admission was temporary or permanent.

b. **Episodic input:**
To capture the breadth of service utilisation for wider community health and OT/SW services, the 12 months preceding data collection data were included.

Due to demand on services, particularly with the existence of long waiting lists, service providers generally (particularly Community Psychiatric Nurses (CPN), physiotherapists, and district nurses) kept individuals on their active caseload only when actually providing care. These episodes began with an initial referral, either by the individual/family or another care provider. Episodes ended with discharge from the care provider either due to need for care ending (including ongoing maintenance treatment provided by someone else), referral elsewhere, or lack of engagement by the individual. Consequently, a care episode can range between a few hours to multiple years. The process of assessment and treatment frequently follows an irregular visiting pattern, with a longer assessment visit, frequent initial visits, with later visits less frequent as the condition improves. Thus, calculating time input for such episodes can be problematic.

c. **Community health services**

   I. For all but DN utilisation, the general method was to verify the number of contacts and time spent during each contact for the year pre-data collection visit, summing them to give a total. This figure was then divided by 12 to give a mean monthly figure (hours).

   II. District nurses can visit people very frequently (twice daily) over a long period, making data verification labour intensive. Thus, the visits for the month prior to the data collection visit were verified, in frequency and time, giving both a mean visit time and monthly total time (hours).

d. **Community occupational therapist and social worker staff**

In the UK, occupational therapists and social workers are registered professionals, working in multiple settings (including local authority and NHS), whose roles can include both supporting local authority long-term care and community health functions. Therefore, attribution of costs to either one function or the other was problematic. Hence, for clarity OT and SW costs were calculated separately to other community health and LTC services, although their roles can contribute to both services and wider care needs.

Limited short-term interventions by Rapid Response or Discharge OT commonly had a verifiable time so were costed in the same way as the community health services process described above. For other interventions, the process outlined under Data Analysis in Methods was used. The medians for each time band were used to calculate a mean staff time estimate of five hours for low-medium participants and 10 hours for medium-high participants, forming the base case estimates. A summary of figures used for sensitivity analysis of OT/SW staff time is provided in Table 2 for ease of reference.

Appendix 2 Table 2: OT/SW staff time input summary of figures used for sensitivity analysis

Band	Lower estimate (hrs)	Mean (base case) estimate (hrs)	Upper estimate (hrs)
Low-medium band	2.5	5.0	7.5
Medium-**high** band	7.5	10.0	12.5

4. Participants resident in care home

a. It is worth noting the following points when considering service utilisation and costing of long-term care provision in residential units, compared with home care provision:

b. Rooms commonly already have wet-floor showers.

c. Some equipment is bought by the care home but has been costed as per community equipment costings as costs will be very similar.

d. Larger items of equipment, such as a mobile hoist, are usually shared between residents. For those participants, to represent this shared capital cost, the full cost has been divided by 10, with 10% allocated to the participant.

e. Costs per week were used to calculate monthly care costs, excluding external services, but including personal living expenses of residents (Curtis and Burns, 2020).

f. Care staff are core to the cost per week/night. However, other staff, including nursing staff are not, so are costed as separate services as per other participants.

g. Costs do not include that frequently more than two staff will be needed for Moving & Handling of residents with higher weight. This can be a contributing reason for admission to residential care.

5. Equipment costings

Costs were obtained from verifiable local sources where possible. Costs from published work were used where no reliable costs could be locally sourced for specific equipment and adaptations (Curtis and Beecham, 2018). This particularly applied for housing adaptions, due to the multiple departments involved.

A separate paper with further detail is planned. Provision of some major equipment and adaptations were significantly delayed due to the Covid-19 lockdown preventing delivery or building work. Where these had been fully assessed and financially approved by the date of data collection, they were included in study costs.

6. Adaptations

Housing adaptations are long-term, permanent fixtures to enable independent living. Thus, any verifiable adaptations occurring from 2010 onwards (usually when electronic records started) were included in costings. Adaptations had to be attributable to participants, and no other family members or previous dwelling occupants.

Processes for planning and managing housing adaptations vary by local authority (Curtis and Beecham, 2018), involving a range of technical staff (grants officer, finance officer, home improvements officer, environmental health staff). A model widely used in England uses a Home Improvement Agency. The OT assesses the clinical need element, planning solutions, with the mechanism for financing and enacting that provision usually separate from them, although they would expect to review the final outcome and sign it off as satisfactory (Curtis and Beecham, 2018).

Adaptation building costs were largely verifiable from local authority records. Where no figures were available, costs from Curtis & Beecham (2018) relating to 2013-2014 prices were used. Costs for minor adaptations such as handrails and door widening were not uprated as differences were unlikely to be material. For costs relating to major adaptations, figures were uprated.

For wet floor showers, a mean figure from 16 recent adaptations in 2020 was provided by the local authority locally of £6,100. This was compared with the mean figure provided by Curtis & Beecham (2018) of £4,651 using 2013-14 costs (Curtis and Beecham, 2018). The £4,651 was uprated using the Building Cost Information Service data in PSSRU Section V (Curtis and Burns, 2020) with the

2019 rate of 2.6% carried forward for 2020, producing £5,983, which is comparable with the local authority figure used.

Where major adaptations were funded by Health Improvement Grants (HIG), exact figures were unavailable from OT records as the related financial agreement is a separate function,

for which participants had not consented. Therefore, an estimate was calculated applying HIG guidance to prospective quotations for adaptations. These may differ from the final figure for work carried out but reflects a fair estimate of monies prospectively approved by the local authority for works.

7. Private help

Data was collected on private arrangements that participants had regarding paying for cleaning or housework but was excluded from this analysis. Due to the Covid-19 lockdown domestic help from external sources was minimal.

8. Costs not included

a. Local authority care costs:

I. Community Alarm service: unable to get local costing due to service pressures. Very little available on published costs, other than charges to individuals for the service. Published costs show large variation depending on structure and model of service provided. Costs are unlikely to be significant per individual, given individuals contribute, although some providers do not charge if the individual receives certain benefits.

II. Annual servicing of electrical equipment: hoists/beds/mattresses and wash/dry toilets (approximately £195 annually).

III. Support from Welfare Rights Team (except social work costs already included) for benefits/income maximisation usually including Disability Living Allowance (both care and mobility components): time input from Welfare Rights team staff was not verifiable.

IV. Wheelie-bin pull out service: to ensure housebound individuals get rubbish uplifted.

b. **Health costs:**

I. Prescription-only products used by district nurses for wound and skin care.

II. GP contacts and GP prescribing.

III. Continence products.

IV. Compression garments prescribed for lymphoedema.

V. Oxygen concentrator/Continuous Positive Airway Pressure (CPAP) equipment as provided through secondary care respiratory budget.

9. Rounding

All costs rounded to nearest pound.

Appendix 2 Table 3 Summary demographics: participants, non-participants and census groups

	Participants	**Non-participants**	**Lymph-oedema census**	**Weight management census**
Number	25	32	58	171
Age range (years)	40-87	32-90	26-91	17-76
Mean age (years)	62	66	66	46
Women % (*n*)	60 (15)	59 (19)	69 (40)	78 (133)
Under 65 years % (*n*)	56 (14)	38 (12)	47 (27)	88 (151)
SIMD 1-5 % (*n*)	68 (17)	84 (27)	78 (45)	66 (113)

Appendix 3

Interview Schedule Help at Home for people living with a higher weight (part of EXPRESSO) Participant Interview – Topic areas

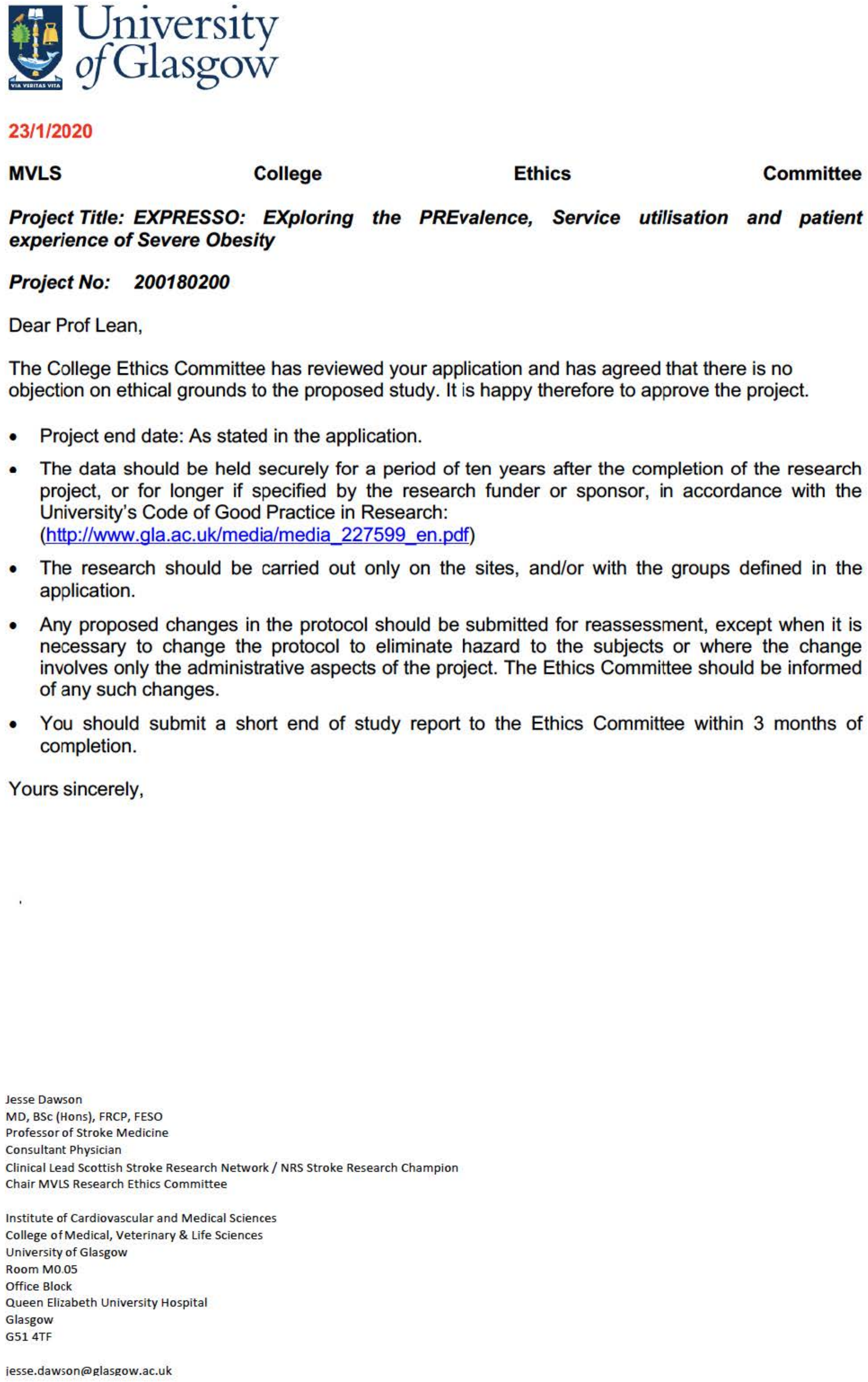
Introduction:
Thank you for being willing to let me interview you today. Your experience is very valuable to us. As someone who is housebound and living with a higher weight, we are interested in your experience of community health and social care services. There are no right or wrong answers. Please answer as honestly as you can. If you would prefer not to answer a question, then please ask to move onto the next question.
All answers are treated confidentially. The only time that I would be allowed to break this, is if I was concerned that you were going to harm yourself or were being harmed by someone and couldn't do anything about it, when I would talk in confidence to your GP. Are you still willing to go ahead?

1. Brief summary of services used from Help at Home questionnaire.
2. Discussion of any issues raised during questionnaire – with further detail.
3. Factors that help access to services.
4. Factors that act as barriers to using services.
5. Can you tell me about how well (or not), services work (ed) together to help you/ care for you?
6.
   a. How did you find the attitude of staff towards your weight?
   b. Have you ever experienced negative attitudes from staff about your weight?
7. To help me understand about what life is like for you day to day, please can you tell me about the physical effect of your higher weight on your ability to look after yourself?
8.
   a. If you feel able, can you describe if/ how living with a higher weight affects your mood and outlook on life?
   b. How does this affect your ability to care for yourself?
9. Is there anything that we haven't covered about living with a higher weight, that you would like to tell me?

Closing:

Thank you very much. Would you like to see the results of this work? *Note on consent form*

Appendix 4



University of Glasgow

23/1/2020

MVLS College Ethics Committee

Project Title: EXPRESSO: EXploring the PREvalence, Service utilisation and patient experience of Severe Obesity

Project No: 200180200

Dear Prof Lean,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: As stated in the application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician
Clinical Lead Scottish Stroke Research Network / NRS Stroke Research Champion
Chair MVLS Research Ethics Committee

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