

Smith, Georgia (2024) *Older people's experiences of mental health services*. D Clin Psy thesis.

https://theses.gla.ac.uk/84607/

Copyright and moral rights for this work are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This work cannot be reproduced or quoted extensively from without first obtaining permission in writing from the author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given



Older people's experiences of mental health services.

Georgia Smith (BSc, MSc)

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

July 2024

TABLE OF CONTENTS

| TABLE OF CONTEN | ITS |
|-----------------|-----|
|-----------------|-----|

| LIST OF TABLES | 1 |
|------------------------------------|----|
| LIST OF FIGURES | 2 |
| ACKNOWLEDGEMENTS | |
| CHAPTER 1 | 4 |
| ABSTRACT | 5 |
| INTRODUCTION | 6 |
| RATIONALE | 9 |
| OBJECTIVES | 9 |
| METHODS | 10 |
| SEARCH STRATEGY | 10 |
| INCLUSION | 10 |
| EXCLUSION | 11 |
| DATA COLLECTION PROCESS | 12 |
| RATING OF METHODOLOGICAL QUALITY | 12 |
| RESULTS | 13 |
| STUDY SELECTION | 13 |
| GENERAL DATA | 15 |
| INSTRUMENTS' STRUCTURE | 21 |
| GENERATION PROCESS | 22 |
| QUALITY OF RESEARCH ARTICLES | 25 |
| DISCUSSION | 29 |
| STRENGTHS AND LIMITATIONS | 31 |
| CLINICAL AND RESEARCH IMPLICATIONS | |
| CONCLUSION | |
| REFERENCES | |
| CHAPTER 2 | |
| PLAIN LANGUAGE SUMMARY | 43 |
| ABSTRACT | 46 |
| INTRODUCTION | 48 |

| AIMS AND RESEARCH QUESTIONS | 50 |
|--|----|
| METHODS | 51 |
| ETHICAL APPROVALS AND CONSIDERATIONS | 51 |
| PARTICIPANTS | 51 |
| PROCEDURE | 52 |
| ANALYSIS | 54 |
| RESEARCHER CHARACTERISTICS AND REFLEXIVITY | 55 |
| RESULTS | 56 |
| RMN FOCUS GROUPS | 56 |
| PATIENT INTERVIEWS | 56 |
| DISCUSSION | 73 |
| LIMITATIONS | 76 |
| IMPLICATIONS FOR FUTURE RESEARCH | 78 |
| CONCLUSION | 78 |
| REFERENCES | 80 |
| APPENDICES | 85 |

LIST OF TABLES

| Table 1.1 General characteristics of instruments | 16 |
|--|----|
| Table 1.2 Instrument quality ratings | 26 |
| Table 2.1 Participant characteristics | 57 |

LIST OF FIGURES

| Figure 1.1 Flowchart of search strategy (PRISMA, 2020) | 14 |
|--|-----|
| | |
| Figure 2.1 Thematic map | сo |
| Figure 2.1 mematic map | .50 |

ACKNOWLEDGEMENTS

I dedicate this work to my wonderful Nanny. All of it is for you.

Thank you to all of the people that made this research project come to life.

To the people that agreed to take part in this research, thank you. Every time I felt stuck in the write up stage, I reminded myself of my sole aim: hoping you feel truly listened to and represented in this work.

To my supervisor, Dr David Grinter, thank you. It has been such a pleasure to work with you on all three of my doctorate projects. It really has felt like teamwork. Whenever I need to remind myself to breathe now, it's your voice I hear (that sounded gushy - I just needed a lot of reminders in three years).

To my research advisor, Dr Lynda Russell. I think we can all agree that you are such a beacon of light for trainees, always at exactly when they need it. Thank you.

To the Older People Psychology Service. What an honour it's been to be aligned to your service these past three years. Thank you for all of your support, guidance, wisdom and friendship.

To all of my family, thank you never faltering in your belief in me. I wouldn't have had the opportunity to do this if it wasn't for you.

To my Stuart! It would take writing another 30,000 word thesis to thank you in all the ways you deserve. Thank you for everything, you really are a dream come true.

3

CHAPTER 1

Measuring older people's experience of mental health care: a systematic and critical review of patient and carer-reported experience measures.

Prepared in accordance with the author requirements for the <u>Journal of</u> <u>Mental Health</u>

ABSTRACT

There is growing interest in measuring patient experience within mental health care and central to doing so is the development of appropriate measurement methods. Whilst numerous patient-reported experience measures (PREMs) are available, systematic reviews examining their psychometric properties have excluded measures designed specifically for older people. This review aimed to identify and critically analyse all available patient and carer-reported patient experience measures designed to, or applicable in, measuring the mental health care experience of older people. Four databases were systematically searched and identified twenty-one reports dealing with the process of development and/or validation of relevant instruments. The methodological quality and psychometric properties of the instruments were assessed according to Pesudovs et al. (2007) quality criteria and results were heterogeneous. An inductive qualitative analysis of instrument content identified ten key domains of patient experience applicable to OPMH: interpersonal/relational aspects, information, patient involvement, service aspects, discharge, goal setting, safety, social support, access and medication. The heterogeneity of study designs highlights the need for greater standardization and rigour of methodological processes for development and validation of PREMs. Further well-designed studies to appropriately validate existing and new PREMs applicable for use within older people mental health services are required.

Keywords: systematic review, patient-reported experience measures (PREMs), older adult mental health, carer-reports

5

INTRODUCTION

Older people mental health services are concerned with the care and treatment of people with complex mixtures of psychological, cognitive, functional, behavioural, physical and social problems, usually relating to ageing (Royal College of Psychiatrists, 2015). They aim to meet the needs of older people with mental health problems, and their carers, in a variety of settings, including community-based services, inpatient facilities, residential care and nursing homes, hospices and the patient's own homes. They must address the needs of people with both neurodegenerative disorders, such as dementia, which is estimated to affect over 55 million people worldwide (World Health Organisation, 2023), as well as mental health disorders such as depression and anxiety, affecting around 14% of adults aged 60 and over (Institute of Health Metrics and Evaluation, 2021). Older people often present to mental health services with psychological difficulties and physical health comorbidities but also in relation to increased disability and frailty. This higher level of complexity is associated with increased health and social care costs, with patients aged 75 and over experiencing longer hospital stays; a higher risk of healthcare associated infections; delayed discharge and institutional care outcomes (Public Health Scotland, 2020).

Healthcare is increasingly understood as an experience, as well as an outcome, and there is evidence of an association between positive patient experience and improved health care outcomes (National Institute for Health Care Research, 2019). Embedded within patient experience is a focus on individualised patient and familycentred care and tailoring of services to meet patient needs and engage them as partners in their care (Wolf et al., 2014). Experiential features of care have been found to be highly valued by patients (Ryan et al., 2014), and research indicates that the experience of receiving care can have a profound impact on the wellbeing of older people with mental health needs. Using survey data Fortuna et al. (2017) compared the patient experience of healthcare services amongst older patients (≥50 years old) with and without serious mental illness. They found that older adults with mental health disorders reported significantly worse provider communication, as well as the greatest barriers to shared decision-making and accessing services. Wilberforce et al. (2018) utilised concept mapping to identify personal qualities and relationships; communication problems; feeling powerless; in-and-out care; bureaucracy; focus on life, not just mental health; and continuity of care as key themes in the care experience of mental health services for older people. However, there continues to remain very little further research beyond this and instruments to evaluate experiential quality in the mental health care of older adults are lacking.

Central to measuring patient experience is the development of appropriate measurement methods. Patient-reported experience measures (PREM) are increasingly and internationally promoted as an important source for identifying, monitoring, and addressing the concerns and priorities that matter to patients and their family caregivers (Friedel et al., 2023). They are used by healthcare providers and researchers to gather information on patients' views of their experience whilst receiving care and thus allow direct feedback with the intention of service improvement (Kingsley & Patel, 2017). Unlike patient-reported outcome measures (PROMs), which look at outcomes of care, and satisfaction measures, which look at whether the care provided has met patients' needs and expectations, PREMs measure impact of the process of the care on the patient's experience. Patient relatives and carers also play an integral role in health care processes, particularly within the older population (National Academies of Sciences, Engineering, and Medicine, 2016) and their views concerning quality of care take on increased importance, particularly when patients have difficulty communicating due to cognitive impairment or illness severity. Findings from qualitative service evaluations in the UK indicate that carers feel they lack a 'voice' in the care of their loved ones, despite findings that the carer's voice can be powerful in contextualising challenges faced and proposing new ways of working (Boughey & McSherry, 2019). Several tools have been developed to assess carer experiences and outcomes of being a carer (Goranitis, Al-Janabi & Coast, 2014; Rand et al., 2015; Malley, Fox & Netten, 2010), and a number of studies have explored carer or relative views on the quality of older adult healthcare (Finnema et al., 2001; From et al., 2015; Lilleheie et al., 2020). However, it is unclear if specific measures have been developed to measure carers or relatives experience of older adult healthcare, and whether these would be applicable for use in an older adult mental healthcare context.

To date, systematic reviews have focused on satisfaction instruments available for use within psychiatric services (Boyer et al., 2009; Miglietta et al., 2018; Sanchez-Balcells et al., 2018); have excluded patient experience measures designed specifically for older people (Fernandes et al., 2020); and have not considered the inclusion of carer-reported experience measures in measuring patient experience of mental health care. Fernandes et al. (2020) recent systematic and critical review of PREMs for use in adult mental health care found that the most consistently covered domain was interpersonal relationships, followed by: respect and dignity, access and care coordination, drug therapy, information, psychological care and care environment. Several instruments included in the review included adults aged 65 years and older in their validation samples (such as the PIPEQ-OS; Bjertnaes, Iversen & Kjollesdal, 2015), however instruments specifically designed for the elderly were excluded from the review. The needs of older people with functional mental illness and/or organic disease and their associated physical and social issues are often distinct from younger people (Joint Commissioning Panel for Mental Health, 2019) and it has been argued that interpretations of patient experience use vocabulary that attends more to the priorities of working-age adults (Nolan, Davies & Grant, 2001), focusing on individuality, recovery, independence and autonomy in care. Furthermore, doubts have been highlighted over the validity of satisfaction measures when used with older people (Williams, Coyle & Healy, 1998).

RATIONALE

Despite the availability of many PREMs, their predominant use has been within adult mental health and to the best of our knowledge, systematic reviews thus far have excluded patient experience measures designed specifically for older people and have not considered inclusion of carer-reported experience measures. Consequently, a knowledge gap exists regarding the selection, validation and use of PREMS and carer-reported experience measures to evaluate older people's experience of mental health services.

OBJECTIVES

The current systematic review aimed to:

- Identify all available patient and carer reported experience measures designed to, or applicable in, measuring the mental health care experience of older adult patients.
- ii. Provide an overview of their content and psychometric properties.

iii. Critically analyse the methodological quality of these instruments using preestablished robust criteria.

METHODS

SEARCH STRATEGY

This systematic review was conducted in accordance with the Preferred Reported Items for Systematic Reviews and Meta-Analyses 2020 updated guidelines (PRISMA; Page et al., 2021; Appendix 1.1). A protocol for this review is registered on Prospero

(https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=513480).

A systematic search strategy was carried out on 5th April 2024. The electronic databases PsycINFO, MEDLINE, CINAHL and Psychological & Behavioural Sciences Collection were accessed using EBSCOhost.

All studies were screened based on the following criteria:

INCLUSION

- i. Samples including older adults aged 65 and over accessing healthcare.
- ii. Samples including carers of older people accessing healthcare.
- iii. Articles dealing with the process of development and/or validation of instruments intended to be used and/or applicable in the context of older adult mental health care. This includes instruments developed for specific care settings (i.e. hospital care, nursing care, residential care).
- To be considered applicable in the context of older adult mental health care,
 instruments must include an element of psychosocial care*.

- v. And they must be designed to capture the experience of patients and/or their carers.
- vi. Any study describing, at least in part, the operationalisation of the construct, item development, pretesting or psychometric analyses were included.

vii. Studies were published in English in a peer reviewed journal.

*For the purposes of this study, we have adopted Matsayi Aji, Muhammad and Abubakar's (2024) definition of psychosocial care: "a holistic approach to healthcare that recognises the interconnectedness of physical, emotional and social-wellbeing and seeks to address all aspects of a person's health and wellbeing."

EXCLUSION

- Instruments specifically designed for adults, children or adolescents (aged under 65 years old) whereby there were no older adults included in the sample.
- ii. Instruments related to physical health conditions only, where there is no element of psychosocial care.
- iii. Instruments not self-reported by patients or carers.
- iv. Articles addressing adhoc instruments.
- v. Grey literature including review articles, editorials, discussion/opinion papers, and conference proceedings.

A systematic search strategy was created using the eligibility criteria for included studies and related keywords were identified from a scoping search. The sensitivity and specificity of the search strategy was examined and amended where necessary by conducting a scoping review of results and ensuring key papers were included. The search terms employed are detailed in Appendix 1.2.

SEARCH PROCESS

Search results were exported to EndNote X9, where de-duplication was completed. Articles were initially screened according to their titles and abstracts and those that did not meet the eligibility criteria were eliminated. A second reviewer (MD) independently screened 10.4% of papers (n= 100) and there was a 97% agreement between the two raters, indicating good inter-rater reliability. Resolution was achieved by a discussion between the two raters, where agreement was reached. The full texts of studies included at this stage were read in full and screened against eligibility criteria.

DATA COLLECTION PROCESS

The remaining studies were included within the review and the data extracted using a data extraction form on Microsoft excel. The Data Extraction Form included study characteristics: general data (author(s) and year of publication, name and abbreviation of the instrument, country and language of origin, study objective(s), characteristics and size of the sample, context, administration method), structure (number of items, number and labels of dimensions/factors, time frame, response scale), development characteristics (viewpoints and sources for item development).

RATING OF METHODOLOGICAL QUALITY

The criteria used to assess the quality of the instruments is derived from the Quality Assessment Criteria framework developed by Pesudovs et al. (2007). Pesudovs et al.'s criteria was originally designed to perform a standardised assessment of the quality of the development process and the psychometric properties of patientreported outcome measures (PROMs) and has since proved to be relevant for evaluating PREMs too (Male et al., 2017; Fernandes et al., 2020). These criteria are presented in Appendix 1.3. Each instrument was independently rated by two authors (GS and JF) as positive ($\nu\nu$), acceptable (ν) or negative (X) against each criterion. There was a 99.39% agreement, indicating good inter-rater reliability. Resolution was achieved by a discussion between the two raters, where agreement was reached.

RESULTS

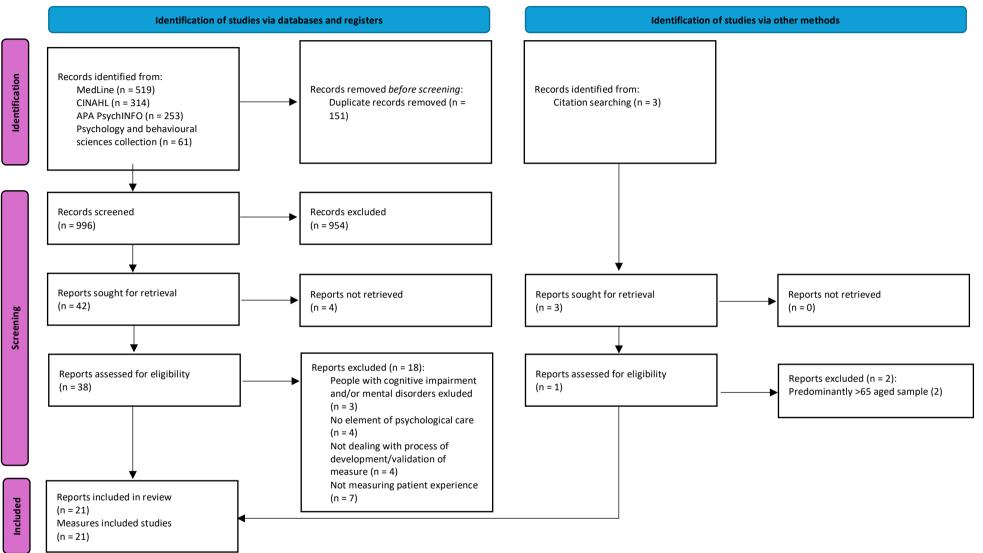
STUDY SELECTION

A total of 1,147 records were identified with the search strategy from electronic databases. Following removal of duplicates, 996 articles were screened by title and abstract against eligibility criteria. This led to the exclusion of 954 articles, which were not relevant. The full text of the remaining 42 articles were sought. Four reports were not available online and a request for access was sent to authors via contact details provided. There was no response received from the authors therefore these four reports were not retrieved. The remaining 38 reports were assessed for eligibility, leading to the exclusion of 18 which did not meet the eligibility criteria. Forward and backward citation searching was conducted for the remaining 20 reports which resulted in identifying three relevant reports. The full text of these three reports were retrieved and assessed for eligibility. Two reports were excluded due to a predominantly <65 aged sample, and the third report was included. Thus, a total of 21 reports were included within this review. For one of the instruments, two reports were included as they separately described development and psychometric properties. In one report, the development of two instruments were reported. Therefore, a total of 21 instruments were critically reviewed. See Figure 1.1 for details on this search process.

Figure 1.1:

Flowchart of search strategy (PRISMA, 2020)





GENERAL DATA

The general characteristics of the instruments are summarised in Table 1.1. Further characteristics of each scale can be found in Appendix 1.4. The instruments included in this review were published between 2003 and 2023. Five of the instruments were developed in the United Kingdom, five in the United States, three in Canada, two in the Netherlands, one in Taiwan, one in Norway, two from Sweden and one instrument that was developed and validated in samples from both Sweden and Norway. The sample sizes ranged from 87 (Lopez et al., 2010) to 1,832 (Teale & Young, 2015) participants. Twelve of the reports did not report on the race or ethnicity of the sample (57.1%). Of the nine that did report on race/ethnicity: four reported samples of predominantly 'white' participants (Oikonomou et al., 2020; Sinclair et al., 2021; Yoon et al., 2015; Lopez et al., 2010); two reported a predominantly white and African American/black population (Torke et al., 2017; Burke et al., 2023); one a sample of Ho-Lo, Hakka and Mainland Chinese participants (Hwang et al., 2012); one a Scandinavian sample (Bergland et al., 2015); and one reported that the development sample included two groups, one serving a predominantly white population and another of south Asian heritage (Wilberforce et al., 2018). The education levels of participants were reported in three reports (Uittenbroek et al., 2016; Torke et al., 2017; Burke et al., 2023), and income was reported in two (Torke et al., 2017; Burke et al., 2023). Sixteen of the reports specified that their sample was 'older' adults (79.2%). For seven reports, older adults was defined as 65 years and older (33.3%); one defined this as 50 and older; one as 60 and older; one 70 and older; and one 75 and older. For five of the reports, the age of the sample was not specified past 'older' adults (23.8%). Five reports reported the mean age of participants (28.8%) and these ranged from 74 to 79.5 years old.

Table 1.1General characteristics of instruments

| Instrument | Reference | Country | Purpose of scale | Sample | Administration method | No. of items | Time frame | Response Scale |
|--|---|-------------|---|--|--------------------------|-----------------|--------------------------------------|---|
| Age-Friendliness Questionnaire (AFQ) | Wright, Fulmer & Boult (2021) | USA | Measure patients experience of the "age- friendliness" of healthcare | 1,632 older (65+) outpatients of geriatrics consult clinic and primary care providers | Self | 5 | Not specified | 5 point Likert (never to always) |
| Person-centre Community Care Inventory (PERCCI) | Wilberforce et al. (2018) | UK | Measure of person- centredness to evaluate older people's experiences of community mental health and social care | 596 older (65+) outpatients accessing integrated older people community mental health and social care services | Self | 18 | Not specified | 4 point Likert (never to always) |
| Patient experiences in psychiatric departments for the elderly (PEPDE) | Ruud, Fjellestad & Hanssen-Bauer (2023) | Norway | Measure of patient experiences of psychiatric inpatient departments for the elderly | 96 elderly (65+) psychiatric inpatients | Self | 20 | Upon or after discharge | Varied 5 point likert for 17 items Dichotomous reponse scale for 3 |
| Patient Assessment of Integrated Elderly Care (PAIEC) | Uittenbroek et al. (2016) | Netherlands | Assess the quality of integrated care from the perspective of elderly people | 223 elderly (75+) patients receiving integrated care and support due to frailty or complex care needs | Self | 20 | Post- intervention (12 months) | 5 point Likert (never to always) |
| Partners at Care Transitions Measure (PACT-M) | Oikonomou et al. (2020) | UK | Assess the experience, quality and safety of care transitions from hospital to home in older patients. | 138 older (65+) patients discharged from hospital | Self or clinician | 8 | Post-discharge | 5 point Likert (strongly disagree – strongly agree) |
| Home (and reablement) Based Patient Reported Experience Measure | Teale & Young (2015) | UK | Evaluate user experience of home-based intermediate care (IC) | 627 users of home-based services | Self | 12 | At discharge | Varied |
| | | | services | Older people but age not specified | | | | |

| Bed-Based Patient Reported Experience Measure | Teale & Young (2015) | UK | Evaluate user experience of bed-based intermediate care services | 1,832 users of bed-based services (social care re- ablement and healthcare hospital-at-home ser- vices) Older people but age not specified | Self | 8 | At discharge | Varied |
|---|------------------------------------|-------------|--|---|----------|----|----------------------------|----------------|
| The CareWell in Hospital (CWH) questionnaire | Bakker et al. (2014) | Netherlands | Assess experiences of frail elderly inpatients in the provision of individualized, integrated care | 470 frail and non-frail medical, surgical and geriatric inpatients (70+) | Self | 8 | Upon or after discharge | Varied |
| Questionnaire concerning patient relatives' perception of the quality of geriatric care | Verho & Arnetz (2003) | Sweden | Measure patient relatives' perception of quality of geriatric care | 318 relatives of patients receiving community geriatric care38 relatives of elderly inpatients Age not specified | Relative | 8 | Not specified | 4-point Likert |
| Case management quality questionnaire (CMQQ) | Hadjistavropoulos et al. (2003) | Canada | Assess elderly client perceptions of the quality of community case management | 174 home care (HC) clients (50+) who had been case managed while in receipt of HC services and 78 long- term care (LTC) clients who were case managed prior to admission to LTC | Self | 30 | Not specified | 5-point Likert |
| Sinclair Compassion Questionnaire (SCQ) | Sinclair et al. (2021) | Canada | Measure patient experiences of compassion in healthcare | 633 participants (mean age = 74) living with a life- limiting illness recruited from acute, home and long-term care settings and a hospice. | Self | 15 | Not specified | 5-point Likert |

| User reported measure of care co-ordination | Crump et al. (2017) | UK | Capture perceptions of care coordination in older service users with one or more chronic conditions | 562 older (65+) people with at least one chronic condition | Self | 46 | Not specified | Varied |
|--|---------------------------|-----------------|---|--|----------------|----|-------------------------|--|
| Family Inpatient Comms Survey (FICS) | Torke et al. (2017) | US | Measure communication experiences of surrogates of older adults in the acute hospital setting | 350 surrogates of hospitalized older (65+) adults | Surrogate | 30 | During hospital stay | 5-point Likert (strongly agree to strongly disagree) |
| Quick FICS-5 | Burke et al. (2023) | US | Measure communication experiences of surrogates of older adults in the acute hospital setting | 364 surrogates of hospitalized older (65+) adults | Surrogate | 5 | During hospital stay | 5-point Likert (strongly agree to strongly disagree) |
| Quick FICS-10 | | | nospital setting | | | 10 | | |
| Patient perspective on care and rehabilitation (PaPeR) | Wressle et al. (2006) | Sweden | Evaluate the patients perspective on geriatric care and rehabilitation | 221 older people (m= 79) recently discharged from geriatric inpatients | Interview | 19 | Post-discharge | 5-point Likert (totally agree to totally disagree) |
| Person-centered Climate Questionnaire - Patient (PCQ-P) LTC validation | Yoon et al. (2015) | US | Measure person-centred care from the perspective of elder nursing home residents | 189 older (m = 79.5) nursing home residents | Self | 17 | Not specified | 6-point Likert |
| Elderly resident-perceived caring scale (EPCS) | Hwang et al. (2012) | Taiwan | Measuring the caring in nurses perceived by elderly residents of long- term care facilities (LTCFs) | 297 elderly (60+) LTCF residents | Interview | 14 | Not specified | 5-point likert (absolutely agree to absolutely disagree) |
| Thriving of Older People Assessment Scale (TOPAS) | Bergland et al. (2015) | Norway & Sweden | Measure LTCF resident experiences of thriving | 259 residents (m = 86), 146 family members and 52 staff from LTCF | Self and proxy | 32 | Not specified | 6-point Likert (disagree completely to agree completely) |

| Empowerment Questionnaire for Inpatients (EQuIP) | Lopez et al. (2010) | UK | Measures levels of empowerment experienced by older adults admitted to a psychiatric ward | 87 older (65+) inpatients with a functional psychiatric diagnosis | Self | 16 | During hospital stay | 4-point Likert |
|--|---------------------------|--------|---|--|----------------|----|-------------------------|----------------|
| Program for All-Inclusive Care of the Elderly (PACE) Satisfaction Survey | Atherly et al. (2004) | US | Measuring the satisfaction of older persons and their family members with capitated care | 165 frail older (age not specified) adults 137 relatives | Self and proxy | 23 | Not specified | 5-point Likert |
| Older Adult Experience Survey | Gilsenan et al. (2021) | Canada | Measure the experience of older adults in appointment-based specialised geriatric services. | 131 frail older adults with complex medical, functional, and psychosocial issues. | Self | 12 | Not specified | Varied |

Eighteen of the instruments were designed to measure patient experience of care (85.7%), thirteen of which were designed to be self-administered (61.9%); one designed to be self- or clinician- administered (Oikonomou et al., 2020); two designed to be self- or proxy-administered (Atherly et al., 2004; Bergland et al., 2015) and two designed to be administered in an interview (Hwang et al., 2012; Wressle et al., 2006). The other three instruments were designed to measure relative (Verho & Arnetz, 2003) and surrogate (Torke et al., 2017; Burke et al., 2023) experiences of care and were designed to be self-administered. The instruments targeted a range of settings, services and populations. Of the 21 instruments, three specifically targeted older people mental health services (14.3%): the PERCCI (Wilberforce et al., 2018) was designed as a measure of person-centredness to evaluate older people's experiences of community mental health and social care; the PEPDE (Ruud, Fjellestad & Hanssen-Bauer, 2023), a measure of patient experiences of psychiatric inpatient departments for the elderly; and the EQuIP (Lopez et al., 2010), a measure of the levels of empowerment experienced by older adults admitted to a psychiatric ward.

Four of the instruments were designed for use in specialist geriatrics services: the AFQ (Wright, Fulmer & Boult, 2021), a measure of patient experience of the 'agefriendliness' of healthcare; the PaPeR (Wressle et al., 2006), a measure of patient perspective on geriatric care and rehabilitation, validated in a sample of geriatric inpatients; the Older Adult Experience Survey (Gilsenan et al., 2021); and Verho & Arnetz's (2003) questionnaire concerning patient relatives' perception of the quality of geriatric care, tested in a sample of both community and elderly inpatients' relatives. Three of the measures were tested in a sample of older adults with frail and/or complex needs: the PAEIC (Uittenbroek et al., 2016), measuring patients perspective on the quality of integrated care; the CWH (Bakker et al., 2014), a

measure of elderly inpatient's experiences of the provision of individualised and integrated care; and Atherly et al.'s (2004) PACE Satisfaction Survey, measuring older people and their family member's satisfaction with capitated care. Three of the measures were designed to measure aspects of patient experience of long-term care facilities: the PCQ-P (Yoon et al., 2015), a measure of person-centred care; the EPCS (Hwang et al., 2012), a measure of perceived caring; and the TOPAS (Bergland et al., 2015) a measure of experiences of 'thriving'. The CMQQ (Hadjistavronoulous et al., 2003) was tested in a sample of home-care and long-term care clients and is designed to measure client perceptions of the quality of community case management. Two of the measures were designed to be a measure of patient experience of intermediate care services (IC-PREMs - Teale & Young, 2015). One of the instruments was designed to measure older people's experience of the transition from hospital to home (PACT-M; Oikonomou et a., 2020); one a measure of perceptions of care coordination in older service users with one or more chronic conditions (Crump et al., 2017); one a measure of patient experiences of compassion in healthcare, tested in a sample of participants living with life-limiting illnesses in acute, home and long-term care settings and a hospice (SCQ; Sinclair et al., 2021) and two a measure of communication experiences of surrogates of older adults lacking capacity in an acute hospital setting (FICS; Torke et al., 2017; Quick FICS; Burke et al., 2023)

The time frame for administering the instrument was reported for 11 instruments: six were designed for completion upon discharge (28.6%), 4 during hospital admission (19%) and one 12 months post intervention (4.8%). Ten of the reports did not specify the time frame for administration (47.6%).

INSTRUMENTS' STRUCTURE

The number of items per instrument ranged from 5 (Burke et al., 2023) to 46 (Crump et al., 2017), with a mean of 17.1 (SD = 10.88). The number of dimensions ranged from 2 (Hwang et al., 2012) to 15 (Sinclair et al., 2021), and these were determined using statistical methods for 19 of the instruments (90.5%). Among them, two reported use of a non-parametric Mokken analysis (Teale & Young, 2015), while the others used exploratory and/or confirmatory factor analyses (81%). Alternatively, three of the instruments established their dimensionality based on a conceptual framework drawn from the literature, alongside group consensus-based methodology, without using statistical methods to confirm their structure (14.3%). Most items used a Likert-type scale (71.4%), among which 10 had a 5-point Likert scale, three had a 4-point Likert scale and two had a 6-point Likert scale. Six instruments used combined response modalities, using both Likert scale on some items and a dichotomous format for others. Some instruments did not provide information on the language used for the Likert scale, but where it was reported, 'never to always' or 'agree to disagree' was used.

GENERATION PROCESS

Evidence of patient involvement in the development process varied between instruments. None of the instruments were developed from a single perspective, all used a combined approach (literature review and/or patients' and/or professionals' perspectives) to varying degrees. The majority of instruments involved patients in some way (85.7%), through qualitative patient and/or carer interviews and focus groups; patient and public involvement advisory groups; patient feedback from piloting; and/or cognitive interviewing. Three did not report on the involvement of patients (Atherly et al., 2004; Bakker et al., 2014; Yoon et al., 2015), however Yoon et al. (2015) did not report any information on the development process, as the purpose of the study was to assess psychometric properties of the instrument in a different population than it was originally designed for. Fifteen of the instruments (71.4%) reported utilising professional/expert perspectives, through panel consultation; professional advisory groups and/or focus groups. Eight studies reported utilising a Delphi method in the development process (38.1%).

Five of the instruments were reported to have been developed from a pre-existing conceptual framework or model (23.81%). Four reported on the development of a new conceptual model for the purposes of instrument development (19%). There were two instruments reported to have been adapted from a pre-existing tool(s) (Uittenbroek et al., 2016; Teale & Young, 2015) and two were developed based on the goal framework of an existing program or intervention (Bakker et al., 2014; Atherly et al., 2004).

PSYCHOMETRIC PROPERTIES

Psychometric properties were assessed and reported with varying levels of evidence. Content validity was reported for fourteen of the instruments (66.7%) and for one instrument this was the only psychometric reported (Crump et al., 2017). Convergent validity was reported for four of the instruments (19%), three of which assessed the degree to which it correlated with a related measure and Pearson's correlation coefficient ranged from 0.45 (Yoon et al., 2015) to 0.87 (Wright, Fulmer & Boult, 2021). The fourth (Verho & Arnetz, 2003) compared an overall quality rating with other questionnaire variables to assess convergent and discriminant validity. Discriminant validity was reported on for a further three instruments (19%). Hadjistavropoulos et al. (2003) reported subscale correlations with other variables all <0.3; Uittenbroek et al. (2016) reported Spearman's rank correlation coefficients of <0.3 and Sinclair et al. (2021) reported r=0.60, p<0.001. Some aspects of criterionrelated validity were examined, and four instruments reported elements of predictive validity (19%), two of which used regression analysis (Wright, Fulmer & Boult, 2021; Verho & Arnetz, 2003) and two calculated Pearson's correlations of total measure scores with outcome measure scores (Torke et al., 2017; Burke et al., 2023).

Reliability measured by internal consistency was documented for 17 of the instruments (81%). Cronbach's alpha coefficient was calculated for 15 of the instruments, and 11 were reported to be within the acceptable value range (0.70– 0.90). One instrument measured internal consistency by calculating an ordinal alpha, reported as >0.90 and considered good. The coefficient of reliability rho (ρ) was calculated for two of the instruments, with scores of 0.76 (Bed-based IC-PREM; Teale & Young, 2015) and 0.81 (Home-based IC PREM; Teale & Young, 2015) both of which are considered acceptable. Stability over time was also examined using test-retest estimates for 5 of the instruments (23.8%), with intraclass correlation coefficients ranging from 0.74 to 0.98. Only one report commented on responsiveness of the scale (Bakker et al., 2014). They used a Mann-Whitney U test to detect differences before and after implementation of a program and found no significant difference (ρ = 0.32).

CONTENT OF THE INSTRUMENTS

An inductive qualitative analysis was conducted of the 106 total dimensions reported. This identified ten key domains of patient experience that could be considered applicable to measuring older people's experience of mental health care. The most represented dimension was interpersonal/relational aspects (27.4%), followed by information (15.1%), patient involvement (8.5%), service aspects (8.5%), discharge (5.7%), goal setting (3.8%), safety (3.8%), social support (2.8%), access (2.8%) and medication (1.9%).

QUALITY OF RESEARCH ARTICLES

The quality ratings of each instrument can be found in Table 1.2. None of the instruments satisfied all criterion of the Pesudovs et al. (2007) framework. Total quality rating scores ranged from 5 to 16 out of 22. Twelve of the instruments (52%) received a quality rating of at least 11 out of 22 (50%). Most instruments scored highly on aspects relating to the quality of development methods. All instruments received a positive (VV) quality rating for specifying the hypothesis pre-study and studying the intended population (100%). Quality ratings were consistently lower for the assessment, reporting or scoring of instrument performance. Instruments that scored poorly on quality, scored negatively (X) on all instrument performance criterion (Teale & Young, 2015; Crump et al., 2017; Bergland et al., 2015; Atherly et al., 2004; Gilsenan et al., 2021). The instruments that scored higher on quality scored positive (VV) or acceptable (V) on several of the instrument performance criterion (Sinclair et al., 2021; Lopez et al., 2010; Hadjistavropoulos et al., 2003; Wilberforce et al., 2018; Wright, Fulmer & Boult, 2021). All but one instrument (Bakker et al., 2014) scored negatively (X) on responsiveness (95.2%) and all but one instrument (Wright, Fulmer & Boult, 2021) scored negatively (X) on predictive validity (95.2%). All but two instruments (Uittenbroek et al., 2016; Hadjistavropoulos et al., 2003) scored negatively on discriminant validity (90.5%).

Table 1.2.

Instrument quality ratings

| Instrument | Pre-study hypothesis | Face validity | Item Identification | Item selection | Unidimensionality | Response Scale | Convergent validity | Discriminant validity | Predictive validity | Test- retest reliability | Responsiveness | Quality rating total score (out of 22) |
|----------------------------|-------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|--------------------------|------------------------|--------------------------------|----------------|--|
| AFQ (Wright, Fulmer & | \checkmark | \checkmark | \checkmark | $\checkmark\checkmark$ | $\sqrt{}$ | \checkmark | $\checkmark\checkmark$ | Х | $\checkmark\checkmark$ | Х | Х | 14 |
| Boult, 2021) | | | | | | | | | | | | |
| PERCCI (Wilberforce et | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | \checkmark | x | х | $\checkmark\checkmark$ | x | 14 |
| al., 2018) | | | | | | | | | | | | |
| PEPDE (Ruud, Fjellestad | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | x | x | x | x | x | 12 |
| & Hanssen-Bauer, 2023) | | | | | | | | | | | | |
| PAIEC (Uittenbroek et al., | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | \checkmark | $\checkmark\checkmark$ | \checkmark | x | $\checkmark\checkmark$ | х | x | х | 10 |
| 2016) | | | | | | | | | | | | |
| PACT-M (Oikonomou et | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | $\checkmark\checkmark$ | $\checkmark\checkmark$ | x | x | х | х | x | 11 |
| al., 2020) | | | | | | | | | | | | |
| Home-based IC-PREM | $\checkmark\checkmark$ | \checkmark | $\checkmark\checkmark$ | \checkmark | x | х | x | x | х | х | x | 5 |
| (Teale & Young, 2015) | | | | | | | | | | | | |
| Bed-based IC-PREM | $\checkmark\checkmark$ | \checkmark | $\checkmark\checkmark$ | \checkmark | x | х | х | x | x | x | х | 5 |
| (Teale & Young, 2015) | | | | | | | | | | | | |

| CWH questionnaire | $\checkmark\checkmark$ | $\sqrt{}$ | \checkmark | Х | \checkmark | \checkmark | х | Х | Х | \checkmark | $\checkmark\checkmark$ | 10 |
|--------------------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|--------------|---|--------------|------------------------|----|
| (Bakker et al., 2014) | | | | | | | | | | | | |
| Verho & Arnetz (2003) | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | $\checkmark\checkmark$ | \checkmark | Х | Х | x | Х | x | 10 |
| CMQQ (Hadjistavropoulos et al., | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | \checkmark | $\checkmark\checkmark$ | $\sqrt{}$ | $\sqrt{}$ | x | х | x | 14 |
| 2003) SCQ (Sinclair et al., 2021) | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\sqrt{}$ | \checkmark | x | \checkmark | х | 16 |
| Crump et al., (2017) | $\checkmark\checkmark$ | $\sqrt{}$ | $\sqrt{}$ | x | x | x | x | х | х | x | x | 6 |
| FICS (Torke et al., 2017) | $\sqrt{}$ | $\sqrt{}$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | \checkmark | \checkmark | х | х | x | Х | 11 |
| Quick FICS (Burke et al., 2023) | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | \checkmark | \checkmark | x | х | x | x | 11 |
| PaPeR (Wressle et al., 2006) | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | x | х | x | x | 11 |
| PCQ-P (Yoon et al., 2015) | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | | $\checkmark\checkmark$ | х | х | х | x | 12 |
| | | | | | | | | | | | | |

| EPCS (Hwang et al., | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | $\checkmark\checkmark$ | \checkmark | Х | Х | х | $\checkmark\checkmark$ | Х | 12 |
|-------------------------|------------------------|------------------------|------------------------|--------------|------------------------|--------------|------------------------|---|---|------------------------|---|----|
| 2012) | | | | | | | | | | | | |
| TOPAS (Bergland et al., | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | \checkmark | \checkmark | \checkmark | х | х | x | x | х | 8 |
| 2015) | | | | | | | | | | | | |
| EQuIP (Lopez et al., | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | \checkmark | \checkmark | \checkmark | $\checkmark\checkmark$ | х | х | $\checkmark\checkmark$ | х | 14 |
| 2010) | | | | | | | | | | | | |
| PACE (Atherly et al., | $\checkmark\checkmark$ | $\checkmark\checkmark$ | х | \checkmark | $\checkmark\checkmark$ | \checkmark | х | Х | х | x | х | 8 |
| 2004) | | | | | | | | | | | | |
| OAES (Gilsenan et al., | $\checkmark\checkmark$ | $\checkmark\checkmark$ | $\checkmark\checkmark$ | х | \checkmark | \checkmark | х | х | х | х | х | 8 |
| 2021) | vv | vv | vv | ~ | v | v | ~ | ~ | ~ | ~ | Λ | 0 |

DISCUSSION

This work provides, for the first time, a descriptive and critical analysis of all available PREMs designed to be used, or considered applicable for use, in the context of older adult mental health care. This included both patient and carer-reported experience measures, which have previously not been considered together. Of the twenty-one measures identified in this review, only three were PREM's designed specifically for measuring older people's experiences of mental health services. This is a stark contrast to the 75 instruments identified in Fernandes et al.'s (2020) recent systematic and critical review of PREM's for use in adult mental health services. Two of the measures focused on measuring a particular aspect of mental health care, separately person-centeredness (Wilberforce et al., 2018) and empowerment (Lopez et al., 2010), and only one measure assessed patient experience more broadly (Ruud, Fjellestad & Hanssen-Bauer, 2023). The quality ratings of the three mental health service specific measures identified in this review were within the higher range (with scores of 14 or above) compared to other measures, however they still vary in psychometric robustness. Important elements were omitted from validation testing of these, and most of the other identified instruments, including testing of discriminant validity, predictive validity and instrument responsiveness. This review also identified three carer-reported measures (Torke et al., 2017; Burke et al., 2023; Verho & Arnetz, 2003) that, content and sample wise, could be considered applicable for use in older adult mental health care. However, the quality of both tools, as assessed by the Pesudovs et al. (2020) framework, is considered poor. Further psychometric testing of both the reliability and validity of these tools is required.

This review considers the complex comorbidities often experienced by older adults with mental health difficulties by including PREMs which have been validated for use in those populations and measure at least one element of psychological care. Nevertheless, the range of instruments identified in this review differ in scope, content and psychometric robustness. It is recognised that the assessment of psychometric properties is essential to support the performance of an assessment measure. Some of the measures demonstrated satisfactory development processes and psychometric properties, whilst others did not meet the recommended criteria. Measures universally scored highly on construct and content validity. Most of the reports that addressed construct validity relied primarily on factor analysis, however, this method alone is not enough to support construct validity. A large percentage of the tools measured reliability by internal consistency and for just over half of the measures, this was reported to be within the acceptable range. Test-retest reliability was not a major objective, as only 5 instruments reported this property. In addition, not all reports provided evidence of consultation with patients and public in the development process. National policy is increasingly encouraging patient and public involvement (PPI) in research and the NHS National Institute for Health Research and other funding bodies now require researchers to have already undertaken PPI or to present a plan for involvement in the proposed research. Whilst all reports included in this review indicated that the tool was not developed from a single perspective, Pesudovs et al. (2007) state that at least three approaches should have been taken for item generation. This includes obtaining sample statements, experiences and opinions directly from: individuals within the target population; experts working in the area and the published literature field. Additionally, precautions should be taken regarding generalisability of instrument that have been tested in a sample with particular characteristics. Most reports did not report on the diversity of their sample in respect to race, ethnicity and socio-economic status and when it was reported on, it was predominantly 'white' population samples.

The results of the qualitative inductive analysis provide interesting insight into the domains most represented in PREMs for use within older adult mental health care. The most represented dimension was interpersonal/relational aspects. Fernandes et al. (2020) also found this to be the most represented dimension for PREMs within adult mental health care, indicating that this is an important experiential aspect of care for both populations. Additionally, information, access and medication were all found to be key dimensions in both this review and Fernandes et al.'s (2020). This review identified patient involvement, service aspects, discharge, goal setting, safety and social support as key dimensions covered by PREMs for use with older people. Those developing new PREMs for use within older people mental health care should consider these dimensions as key aspects of experiential care within this population.

STRENGTHS AND LIMITATIONS

To our knowledge, this is the first review to identify and evaluate instruments designed to be used, or considered applicable for use, in the context of older adult mental health services, for a range of conditions and health complexities, and in multiple care settings. A standardized methodology and robust quality criteria was used to evaluate the performance of currently available and relevant PREMs. The adapted version of Pesudovs et al. (2007) framework has been used several times prior in other recent and relevant systematic reviews (Male et al., 2017; Fernandes et al., 2020). It was utilised in this review due to its simplified scoring system, allowing for a rigorous evaluation with more flexibility than other methods, such as the COSMIN checklist (Mokkink et al., 2018), which is based on the "worst score" principle.

One significant limitation was the language restriction on searchers to English language only. This was applied to obtain a homogenous pool of items and due to time and cost restraints. However, comprehensiveness of the search is demonstrated by the identification of PREMs from seven different countries and through having no date limitations on the search. In addition, backward and forward citation searching was carefully conducted to expand the scope of the search, which lead to the identification of one further eligible report. Patient experience is a somewhat recent term for which there is no commonly accepted definition and no appropriate MeSH thesaurus. This limited the number of results in scoping searches, therefore we included terms related to 'patient satisfaction' to broaden the scope of the results. The content analysis of the instruments was based on a categorisation derived from the data of the inductive qualitative analysis and the results were consistent with the dimensions commonly found in the reports. However, this analysis method is open to bias, despite the rigorous methodology used. Finally, completing an assessment of the quality of the development process and psychometric properties, depends on the quality and accuracy of publications. It is possible that some instruments may not have been properly evaluated due to insufficient reporting or due to an inability to access relevant supporting documentation.

CLINICAL AND RESEARCH IMPLICATIONS

Whilst a number and range of PREM's appear, at face value, to be applicable for use within OPMH services, quality appraisals completed within this review do not fully support the validity and reliability of these tools. Instruments may provide clinicians with useful information regarding older people's experience of the mental health care, however they should be used with caution. Further primary studies examining the psychometric performance would be beneficial before the results obtained can be confidently used to inform practice. In particular, this review highlights the current gap in studies assessing the discriminant validity, predictive validity and instrument responsiveness. Future research should consider further psychometric testing of instrument performance for existing PREMs which have been adequately developed, particularly those that have provided significant evidence of PPI in the development process. When developing new PREMs, researchers should prioritise increasing accessibility and inclusivity of PPI, as well as participants from different cultural and socio-economic groups, to increase generalisability and utility of instruments.

CONCLUSION

The heterogeneity of study designs highlights the need for greater standardization and rigour of methodological processes for development and validation of PREMs. This review also shows that although instruments may achieve distribution for use, they are not all validated using minimum standardized psychometric methods, meaning that they must be interpreted and used with caution. There is a need for further well-designed studies to appropriately validate existing and new PREMs applicable for use within older people mental health services.

REFERENCES

Aji, L. M., Muhammad, A. B., & Abubakar, H. (2024). *Psychosocial care*. In E. Önal (Ed.), *Tertiary care: Medical, psychosocial, and environmental aspects*. IntechOpen. https://doi.org/10.5772/intechopen.110957

Bakker, F. C., Persoon, A., Schoon, Y., Marcel, G. M., & Rikkert, O. (2014). The CareWell in hospital questionnaire: a measure of frail elderly inpatient experiences with individualized and integrated hospital care. *Journal of Hospital Medicine*, *9*(5), 324-329. https://doi.org/10.1002/jhm.2158

Bergland, Å., Kirkevold, M., Sandman, P. O., Hofoss, D., & Edvardsson, D. (2015). The thriving of older people assessment scale: validity and reliability assessments. *Journal of Advanced Nursing*, *71*(4), 942-951. <u>https://doi.org/10.1111/jan.12593</u>

Bjertnaes, O., Iversen, H., & Kjollesdal, J. (2015). PIPEQ-OS – an instrument for on-site measurements of the experiences of inpatients at psychiatric institutions. *BMC Psychiatry*, *15*, 234. https://doi.org/10.1186/s12888-015-0621-8

Boughey, A., & McSherry. (2019). External Report Commitment to Carers: The Carers' Voice Network. <u>https://www.england.nhs.uk/midlands/wp-</u> <u>content/uploads/sites/46/2019/05/report-to-carers-voice-network.pdf</u>

Boyer, L., Baumstarck-Barrau, K., Cano, N., Zendjidjian, X., Belzeaux, R., Limousin, S., Magalon, D., Samuelian, J.C., Lancon, C., & Auquier, P. (2009). Assessment of psychiatric inpatient satisfaction: a systematic review of self-reported instruments. *European Psychiatry, 24* (8), 540-549.

Burke, E. S., Slaven, J. E., Taylor, T. A., Monahan, P. O., Sachs, G. A., & Torke, A. M. (2023). The Quick FICS: 5 and 10 Item Versions of the Family Inpatient Communication

Survey. Journal of Pain and Symptom Management, 66(4), e461-

e468. https://doi.org/10.1016/j.jpainsymman.2023.06.020

Crump, H., King, J., Graham, C., Thorlby, R., Raleigh, V., Redding, D., & Goodwin, N. (2017). Developing a user reported measure of care co-ordination. *International Journal of Integrated Care*, *17*(1). <u>https://doi.org/10.5334/ijic.2469</u>

Fernandes, S., Fond, G., Zendjidjian, X., Baumstarck, K., Lançon, C., Berna, F., Schurhoff, F., Aouizerate, B., Henry, C., Etain, B., Samalin, L., Leboyer, M., Llorca, P., Coldefy, M., Auquier, P., & Boyer, L. (2020). Measuring the Patient Experience of Mental Health Care: A Systematic and Critical Review of Patient-Reported Experience Measures. Patient Prefer Adherence, *3*(14), 2147-2161. doi: 10.2147/PPA.S255264.

Finnema, E., de Lange, J., Dröes, R., Ribbe, M., van Tilburg W. (2001) The quality of nursing home care: do the opinions of family members change after implementation of emotion-oriented care? *Journal of Advanced Nursing*, *35*(5), 728-40. doi: 10.1046/j.1365-2648.2001.01905.x.

Fortuna, K., Lohman, M., Batsis, J., DiNapoli, E., DiMilia, P., Bruce, M., & Bartels, S. (2017). Patient experience with healthcare services among older adults with serious mental illness compared to the general older population. *The International Journal of Psychiatry in Medicine*, *52*(4-6), 381-398. doi: 10.1177/0091217417738936.

Friedel, A., Siegel, S., Kirstein, C., Gerigk, M., Bingel, U., Diehl, A., Steidle, O.,
Haupeltshofer, S., Andermahr, B., Chmielewski, W., Kreitschmann-Andermahr, I.
(2023). Measuring Patient Experience and Patient Satisfaction-How Are We Doing It
and Why Does It Matter? A Comparison of European and U.S. American Approaches. *Healthcare (Basel), 8, 11*(6), 797. doi: 10.3390/healthcare11060797.

From, I., Wilde-Larsson, B., Nordstrom, G., & Johansson, I. (2015). Formal caregivers' perceptions of quality of care for older people: associating factors. *BMC Research Notes, 8,* 623. https://doi.org/10.1186/s13104-015-1597-7

Goranitis, I., Al-Janabi, H., Coast, J. (2014). An investigation into the construct validity of the Carer experience scale (CES). *Quality of Life Research, 23*(6), 1743-52. https://doi.org/10.1007/s11136-013-0616-1

Hadjistavropoulos, H. D., Sagan, M., Bierlein, C., & Lawson, K. (2003). Development of a case management quality questionnaire. *Care Management Journals*, *4*(1), 8-

17. https://www.doi.org/10.1891/cmaj.4.1.8.57475

Hwang, H. L., Tu, C. T., Chen, S., & Wang, H. H. (2012). Caring behaviors perceived by elderly residents of long-term care facilities: Scale development and psychometric assessment. *International Journal of Nursing Studies*, *49*(2), 183-

190. https://doi.org/10.1016/j.ijnurstu.2011.08.013

Institute of Health Metrics and Evaluation. (2021). *Global Health Data Exchange* (*GHDx*). Retrieved 20 October, 2023, from: <u>https://vizhub.healthdata.org/gbd-results/</u>

Joint Commissioning Panel for Mental Health. (2019). *Guidance for commissioners of* older people's mental health services. <u>https://www.rcpsych.ac.uk/docs/default-</u> <u>source/members/faculties/old-age/old-age-jcp-for-mental-</u>

health.pdf?sfvrsn=8242f3c2 4

Kingsley, C., & Patel, S. (2017). Patient-reported outcome measures and patient-reported experience measures. *BJA Education*, *17*, 137–144. doi: 10.1093/bjaed/mkw060.

Lilleheie, I., Debesay, J., Bye, A. et al. (2020). Informal caregivers' views on the quality of healthcare services provided to older patients aged 80 or more in the hospital and 30 days after discharge. *BMC Geriatrics, 20*, 97. <u>https://doi.org/10.1186/s12877-020-1488-1</u>

Male. L., Noble, A., Atkinson, J., & Marson, T. (2017). Measuring patient experience: a systematic review to evaluate psychometric proper- ties of patient reported experience measures (PREMs) for emergency care service provision. *International Journal for Quality in Health Care, 29*(3), 314-

326. https://doi.org/10.1093/intqhc/mzx027

Malley J., Fox D. & Netten A. (2010) Developing a Carers' Experience Performance Indicator. Personal Social Services Research Unit, University of Kent, Kent, UK.

Miglietta, E., Belessiotis-Richards, C., Ruggeri, M., Priebe, S. (2018). Scales for assessing patient satisfaction with mental health care: A systematic review. *Journal of Psychiatric Research, 100,* 33-46. https://doi.org/10.1016/j.jpsychires.2018.02.014

Mokkink, L., Prinsen, C, Patrick, D., Alonso, J., Bouter, L., de Vet, H., & Terwee, C. (2018). COSMIN methodology for systematic reviews of Patient-Reported Outcome Measures (PROMs) - User manual. <u>https://www.cosmin.nl/wp-</u>

content/uploads/COSMIN-syst-review-for-PROMs-manual version-1 feb-2018-1.pdf.

National Academies of Sciences, Engineering, and Medicine. (2016). *Families Caring for an Aging America*. Washington, DC: The National Academies Press. https://doi.org/10.17226/23606. National Institute for Health Research. (2019). National Standards for Public Involvement in Research: UK Standards for Public

Involvement. <u>https://sites.google.com/nihr.ac.uk/pi-standards/home</u>

Nolan, M., Davies, S., Grant, G. (2001). Work with Older People and their Families. Buckingham: Open University Press. pp. 4–18.

Oikonomou, E., Page, B., Lawton, R., Murray, J., Higham, H., & Vincent, C. (2020). Validation of the Partners at Care Transitions Measure (PACT-M): assessing the quality and safety of care transitions for older people in the UK. *BMC Health Services Research*, *20(1)*, 1-13. <u>https://doi.org/10.1186/s12913-020-05369-1</u>

Page, M., McKenzie, J., Bossuyt, P., Boutron, I., Hoffmann, T., Mulrow, C. et al. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, *372* (71). https://doi.org/10.1136/bmj.n71

Pesudovs, K., Burr, J. M., Harley, C., & Elliott, D. B. (2007). The development, assessment, and selection of questionnaires. *Optometry and Vision Science*, *84*(8), 663-674. https://doi.org/10.1097/OPX.0b013e318141fe75

Rand, S., Malley, J., Forder, J., Netten, A. (2015). Factor structure and construct validity of the adult social care outcomes toolkit for carers (ASCOT-carer). *Quality of Life Research.* 24(11), 2601-14. doi: 10.1007/s11136-015-1011-x

Royal College of Psychiatrists. (2015). *Criteria for old age psychiatry services in the UK.* <u>https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/old-age-</u> <u>challenging-ageless-services-criteria-for-old-age.pdf?sfvrsn=1e602061_4</u>

Ruud, T., Fjellestad, I. K., & Hanssen-Bauer, K. (2023). Patient experiences in psychiatric departments for the elderly (PEPDE): development, properties, and use of

<u>023-04633-y</u>

Ryan, M., Kinghorn, P., Entwistle, V. A., & Francis, J. J. (2014). Valuing patients' experiences of healthcare processes: towards broader applications of existing methods. *Social Science and Medicine*, *106*, 194-203.

https://doi.org/10.1016/j.socscimed.2014.01.013

Sanchez-Balcells, S., Callarisa Roca, M., Rodriguez-Zunino, N., Puig-Llobet, M., Lluch-Canut, M., & Roldan-Merino, J. (2018). Psychometric properties of instruments measuring quality and satisfaction in mental health: A systematic review. J Journal of Advanced Nursing, 74(11), 2497-2510. doi: 10.1111/jan.13813.

Sinclair, S., Hack, T. F., MacInnis, C. C., Jaggi, P., Boss, H., McClement, S., ... & Thompson, G. (2021). Development and validation of a patient-reported measure of compassion in healthcare: the Sinclair Compassion Questionnaire (SCQ). *BMJ open*, *11*(6), e045988. <u>https://doi.org/10.1136/bmjopen-2020-045988</u>

Staniszewska, S., Bullock, I., Avital, L., & O'Flynn, N (2013). Developing and implementing NICE guidance on patient experience. [Accessed April 18, 2013]. <u>http://patientexperienceportal.org/article/devleoping-and-implementing-nice-guidance-on-patient-experience</u>.

Teale, E. A., & Young, J. B. (2015). A Patient Reported Experience Measure (PREM) for use by older people in community services. *Age and Ageing*, *44*(4), 667-

672. https://doi.org/10.1093/ageing/afv014

Torke, A. M., Monahan, P., Callahan, C. M., Helft, P. R., Sachs, G. A., Wocial, L. D., ... & Burke, E. S. (2017). Validation of the family inpatient communication survey. *Journal* of pain and symptom management, 53(1), 96-

108. https://doi.org/10.1016/j.jpainsymman.2016.08.010

Uittenbroek, R. J., Reijneveld, S. A., Stewart, R. E., Spoorenberg, S. L., Kremer, H. P., & Wynia, K. (2016). Development and psychometric evaluation of a measure to evaluate the quality of integrated care: the Patient Assessment of Integrated Elderly Care. *Health expectations*, *19*(4), 962-972. <u>https://doi.org/10.1111/hex.12391</u>

Verho, H., & Arnetz, J. E. (2003). Validation and application of an instrument for measuring patient relatives' perception of quality of geriatric care. *International Journal for Quality in Health Care*, *15*(3), 197-

206. https://doi.org/10.1093/intqhc/mzg030

Wilberforce, M., Batten, E., Challis, D., Davies, L., Kelly, M., Roberts, C. (2018) The patient experience in community mental health services for older people: a concept mapping approach to support the development of a new quality measure. BMC Health Services Research, 18(1), 461. https://doi.org/10.1186/s12913-018-3231-6

Wilberforce, M., Challis, D., Davies, L., Kelly, M. P., & Roberts, C. (2018). The preliminary measurement properties of the person-centred community care inventory (PERCCI). *Quality of Life Research, 27*, 2745-2756. <u>https://doi.org/10.1007/s11136-018-1917-1</u>

Williams, B., Coyle, J., & Healy, D. (1998). The meaning of patient satisfaction: an explanation of high reported levels. *Social Science & Medicine, 47*(9), 1351-9. doi: 10.1016/s0277-9536(98)00213-5.

World Health Organisation. (2023). *Dementia*. <u>https://www.who.int/news-room/fact-</u>sheets/detail/dementia

Wolf, J., Niederhauser, V., Marshburn, D., LaVela, S. (2014). Defining Patient Experience. *Patient Experience Journal, 1*(1), 7-19. https://doi.org/10.35680/2372-0247.1004

Wressle, E., Eriksson, L., Fahlander, A., Rasmusson, I. M., Tedemalm, U., & Tängmark, K. (2006). Patient perspective on quality of geriatric care and rehabilitation– development and psychometric testing of a questionnaire. *Scandinavian journal of caring sciences*, *20*(2), 135-142. <u>https://doi.org/10.1111/j.1471-6712.2006.00390.x</u>

Wright, M. C., Fulmer, T., & Boult, C. (2021). Preliminary validation of a patientreported measure of the age-friendliness of health care. *Journal of the American Geriatrics Society*, *69*(1), 180-184. https://doi.org/10.1111/jgs.16881

Yoon, J. Y., Roberts, T., Grau, B., & Edvardsson, D. (2015). Person-centered Climate Questionnaire-Patient in English: A psychometric evaluation study in long-term care settings. *Archives of Gerontology and Geriatrics*, *61*(1), 81-

87. https://doi.org/10.1016/j.archger.2015.03.010

CHAPTER 2

A qualitative exploration of older people's experience of discharge from mental health inpatient settings.

Prepared in accordance with the author requirements for the <u>International Journal of Qualitative Studies on Health and Well-being</u>.

Title

A qualitative exploration of older people's experience of discharge from mental health inpatient settings.

Background

In recent years, researchers have become more interested in documenting and understanding patient experiences of mental health care. However, very little research has explored how patients experience inpatient mental health care, particularly for older people. There is a drive within NHS Scotland, in line with Government policy, to shift the balance of care away from inpatient settings to community settings, reduce the length of inpatient stays and improve the discharge process for those that require admission (The Scottish Government, 2021).

Aims and Questions

This study aimed to explore and understand older people's (OP) experience of being discharged from psychiatric hospital, by asking OP themselves, as well as registered mental health nurses (RMN).

Methods

People invited to take part in the study were:

 OP (aged 65 and over) who have been discharged from an OP psychiatric ward in NHS Greater Glasgow and Clyde (NHSGGC), within the last 1 – 12 months. They were recruited through their community mental health team and deemed them as psychologically well enough and able to consent to

43

participation. They were invited to an interview to discuss their recent experience of discharge.

2. RMNs working in OP psychiatric wards in NHSGGC. They were invited to a oneoff focus group to discuss the hospital discharge and transition process, particularly, patients experience of it.

Results

No RMNs took part in this research.

Seven OP took part in this research. Six key themes were identified from the interviews:

- Discharge is a gradual process, something that is worked up to. This involves an initial conversation about discharge; passes; getting the right medication; an occupational therapy assessment of day-to-day functioning and being assigned a community psychiatric nurse (CPN).
- The importance of patient involvement in discharge planning. This includes working collaboratively with doctors and feeling empowered to make decisions.
- Communication: Participants felt communication from hospital staff to patients and their families/carers, regarding plans for passes and discharge, could be improved.
- 4. The importance of social support: Support from family, friends, neighbours and religious and social groups were an important part of the discharge process.
- 5. The importance of community mental health support: Participants spoke of the value of knowing support was both available and accessible from community mental health services, particularly CPN support.

6. The importance of readiness for discharge: Not all participants felt ready for discharge and this impacted on the way they felt after being discharged. The above themes played appeared to play role in whether people felt ready to be discharged.

Conclusions

The results of this research help services to better understand how older people experience discharge from a psychiatric hospital, and how services could improve this process to ensure patients are involved and supported appropriately. It also shows the importance of asking patients about their experience of mental health care.

References

Scottish Government. (2021). *Delivering the right care in the right setting*. Retrieved from: https://www.gov.scot/news/delivering-the-right-care-in-the-right-setting/

ABSTRACT

Background: In recent years there has been a welcome interest in documenting, understanding, and using as a catalyst of service development and change, the patient voice within community mental health settings. However, there remains a notable lack of literature documenting the lived experience of inpatient mental health care, particularly so within Older People's Mental Health (OPMH) inpatient settings. There is a drive within NHS Scotland to shift the balance of care away from inpatient settings to community settings and improve the discharge process for those that require admission (The Scottish Government, 2021). Aims: This study intended to gain insight into older people's experience of being discharged from OPMH inpatient settings by asking patients and Registered Mental Health Nurses (RMN) to share their experiences. Methods: We interviewed seven people recently discharged from NHS Greater Glasgow & Clyde's OPMH inpatient wards. They were asked to share their experiences of: preparing for discharge; the care and support they did, or did not, receive during this process; the transition from hospital to community; and what they think services could and should learn from their experiences of leaving hospital. **Results:** Using reflexive thematic analysis, six main themes were identified from patient data: discharge as a gradual process; feeling involved in discharge planning; communication; social support; importance of CPN support and importance of readiness for discharge. No RMNs partook. Conclusions: This is the first study to have explored older people's experiences of being discharged from mental health hospital and it provides valuable insight into the way in which older people categorise their experience of discharge, as well as how services could improve this process to ensure patients are involved and supported appropriately.

Keywords: Patient experience, older adult mental health, inpatient, discharge

46

INTRODUCTION

In line with government policy, reducing the length of time patients stay in hospital has been a key priority for NHS Scotland for many years. The Scottish Government (2021) has recently introduced two new programmes – "Interface Care" and "Discharge without Delay" – which aim to explore alternatives to inpatient care and improve the discharge process for those who require admission. Hospitalisation has been linked to disrupted sleep, poor nourishment, changes to medication, mentally challenging situations and deconditioning associated with inactivity and bed rest (Krumholz, 2013). At present, emergency admissions for the elderly population are a particular focus. Mental health problems in older people present with higher levels of complexity and associated health and social care costs, with patients aged 75 and over experiencing longer hospital stays; a higher risk of healthcare associated infections; delayed discharge and institutional care outcomes (Public Health Scotland, 2020). The proportion of older adults within acute hospitals is over 40%, and almost 40% are discharged to a higher level of care than they had on admission (Royal College of Psychiatrists, 2019). Strategies aimed at reducing the likelihood of hospital admissions have received a considerable amount of research attention, including innovations for more collaborative or user-focused approaches (Wright et al., 2015). The transition period, from inpatient mental health to the community, has been found to be the greatest risk for adverse outcomes including relapse, rehospitalisation and suicide (Chung et al., 2017). Osborn et al. (2021) found that within their UK sample, 21.4% of individuals discharged from inpatient mental health care settings were readmitted within 6 months and older age was identified as a statistically significant risk factor for readmission. Loneliness, limited social networks and difficulties attending appointments due to lack of transport (Beebe, 2010) have been cited as

48

reasons as to why the post-discharge period is so difficult. Older adults are at an increased risk of all these stressors.

Quantitative methods have typically been used in psychiatric discharge research and have covered a range of topics including rates of suicide, hospital readmission and effectiveness of discharge interventions (Meehan et al., 2006; Pushner at al., 2011). However, very few studies have sought to consider and explore patient experience of discharge and transition from inpatient to community. Evidence has demonstrated that patient experience feedback can assist services to better meet needs; results in more efficient and effective use of services; and can positively affect length of hospital stay (Doyle, Lennox & Bell, 2013). Redding, Maguire, Johnson and Maguire (2017) utilised IPA to understand the lived experience of adults (mean age of 46) who were recently discharged from mental health inpatient settings. They highlighted many common themes between participant's accounts including difficulties with adapting to the community and the importance of support on discharge. Participants felt a linked care between inpatient and community would have eased anxiety. The Mental Welfare Commission for Scotland's (2019) paper on people's lived experience of psychiatric hospital also highlighted people's expressions of need for access to adequate care and support on discharge. Transitions in care involve a multitude of health and social care professionals working within and across different organizational boundaries (Waring, Marshall & Bishop 2015). The King's Fund (2015) brought to light the pressures that hospitals face when discharging and transferring patient care which has led to inappropriate assessments and readmissions and a lack of communication between health and social care sectors.

The limited research available on the patient experience within older people mental health care thus far has focused on community services. Comparisons between the patient experience of older people (≥50 years old) with and without serious mental illness in the United States indicate that older adults with mental health disorders report significantly worse provider communication, as well as the greatest barriers to shared decision-making and accessing services (Fortuna et al., 2017). Communication problems were also reported as a key care experience for older adults accessing community mental health services in the United Kingdom (Wilberforce et al., 2018), together with personal qualities and relationships; feeling powerless; in-and-out care; bureaucracy; focus on life, not just mental health; and continuity of care. To our knowledge, there have been no studies exploring older people's experience of the discharge and transition process from mental health inpatient settings to community, despite the risks associated.

AIMS AND RESEARCH QUESTIONS

The current study had three main aims:

- To explore older people's experience of the discharge process and transition from mental health inpatient to community settings.
- To explore the views of the Registered Mental Health Nurses (RMN) working in older people mental health inpatient settings.
- To understand if RMN's and patients share similar or different views on the discharge and transition process and how patients experience it.

Specific research questions were as follows:

 How do older people characterise their experience of discharge from a mental health inpatient hospital?

- 2. What, if any, aspects of the process do they describe as beneficial or unhelpful?
- 3. How do nurses perceive patient experiences of discharge?
- 4. What similarities and differences are reported by patients and nurses?

METHODS

ETHICAL APPROVALS AND CONSIDERATIONS

Ethical approval was obtained from the West of Scotland Research Ethics Service (reference: 24/WS/0003, IRAS: 330114; Appendix 2.1) and management approval obtained from NHS GG&C Research and Innovation (Appendix 2.2). Informed consent was obtained from all participants (Appendix 2.3) and the recording and electronic storage of confidential patient information adhered to the Data Protection Act 2018 (UK Government, 2018) and the General Data Protection Regulation (GDPR, 2018).

PARTICIPANTS

Participants invited to one-to-one interview were patients who had been discharged from one of the six older people's functional mental health inpatient wards in NHS Greater Glasgow and Clyde (NHSGGC). These wards provide assessment and treatment for older people with acute 'functional' mental illness. The term 'functional' mental illness applies to mental health disorders other than dementia, such as mood disorders (Hatfield & Dening, 2011). Patients invited to participate must have been discharged from inpatient to community care within the 12 months preceding the interview, however those discharged within one month were excluded, as to not disrupt their transition process. Participants were aged 65 or over at the time of discharge, recruited through NHSGGC Older People Community Mental Health Team's (OPCMHT) and must have been deemed by care coordinators as psychologically well enough to participate. Patients diagnosed with dementia, experiencing delirium, florid psychosis, problematic substance use or lacking capacity to consent (as determined by their care team) were excluded. Guest, Namey and Chen's (2020) findings from a bootstrapping analysis on thematically coded qualitative datasets indicate that 6–7 interviews capture the majority of themes in a homogenous sample. We therefore aimed to recruit between 6-8 participants, to account for potential participant withdrawal from the study.

Participants invited to focus group interviews were RMN's working in the six OPMH inpatient wards in NHSGGC at the time of data collection. We sought to understand a nursing perspective as they are the clinicians directly coordinating and delivering care during the discharge process. We aimed to hold two focus groups with a maximum of 10 attendees per group. Staff that were employed via bank or agency were excluded.

PROCEDURE

Patients

The eligibility criteria and patient information sheet (PIS; Appendix 2.4) were circulated to OPCMHT clinicians via email (Appendix 2.5) and clinicians were asked to share the PIS with suitable potential participants. Participants were asked to 'opt-in' to the study by i) contacting the researcher or ii) providing verbal consent for clinicians to share their contact details with the researcher, for them to make initial contact. The researcher contacted all interested participants via telephone, providing opportunity for questions regarding participating. Participants were invited to choose the date, time and mode of interview. Modes of interview offered were: face-to-face in clinic meeting room at a health or resource centre of their choice, or videocall using Microsoft Teams. Participants were provided with the opportunity to claim travel expenses to and from the interview location. Participants were also invited to bring a loved one or carer to the interview to provide support if required.

A semi-structured interview schedule (Appendix 2.6) was developed in consultation with an expert by experience employed by the Mental Health Network. They provided guidance on the use of appropriate language/jargon, as well as an insight into common hospital experiences and/or journeys for older people, to ensure the questions allowed participants an opportunity to discuss this. Utilising this interview schedule, participants were asked to discuss their experience of: preparing for discharge; the care and support they did, or did not, receive during this process; the transition from hospital to community; and what they think services could and should learn from their experiences of leaving hospital. Participants were informed that it was their experiences that the researchers were seeking to understand, so although the interview was semi-structured, the content could be guided by them, including decisions on what they did not wish to discuss.

All interviews were conducted by one researcher (GS) and were audio recorded and transcribed verbatim by the same researcher, with identifying information removed, de-specified or pseudo-anonymised. Participants were asked to complete written consent forms (Appendix 2.3); were provided with a copy; and advised to contact the researcher if they had any concerns regarding the content following the interview. The interviewer spent a brief period before each interview building rapport with participants, as well as providing a chance to reflect on their interview once it had been completed. Participants were also provided with a post-interview support resource (Appendix 2.7) which provided guidance and contact numbers for accessing support, as well as the complaints procedure and contact details for NHSGGC.

RMNs

Ward managers were contacted via email (Appendix 2.8) and asked to identify and provide contact details of potential participants. Thirty-six potential participants were identified and contacted via email (Appendix 2.9) on five occasions over a fourmonth period. On the first occasion the PIS was provided and participants were asked to contact the researcher if they were interested in participating. One prompt email was sent, followed by two follow up emails providing a choice of two dates for attendance to focus groups. Members of NHSGGC's Older People Inpatient Psychology (OPIP) service assisted with recruitment by disseminating the PIS with suitable participants during multidisciplinary ward team meetings. An interview schedule was designed (Appendix 2.10) and interested participants were asked to complete a written consent form (Appendix 2.11)

ANALYSIS

Interview data were analysed using Braun and Clarke's (2006; 2022) six-phase process of reflexive thematic analysis: familiarisation with the dataset; coding; generating initial themes; developing and reviewing themes; refining, defining and naming themes; and write up. This approach has been widely used and accepted as robust across a wide range of disciplines (Braun & Clarke, 2013). Braun and Clarke's (2006) 15-point checklist for reflexive thematic analysis was utilised to ensure fidelity to the approach (Appendix 2.12). Given that there is little, to no, prior research in this area, an inductive, semantic and data-driven approach was taken, whilst also recognising the role of the researcher in co-creation of themes (Braun & Clarke, 2013). Analysis was conducted within an experiential, realist and essentialist qualitative framework, aiming to capture and explore patient and staff's own perspectives, understandings and reality.

RESEARCHER CHARACTERISTICS AND REFLEXIVITY

In reflexive TA, the researcher plays an active role in the production of knowledge, where codes are understood as interpretations of patterns of meaning across the dataset (Braun & Clarke, 2019). Reflexivity involves critically examining how one's own experiences, knowledge and social positioning influence the research process. In the current study, the researcher's positionality is shaped by their identity as a young, white British female with a middle-class background, holding a postgraduate education, and working as a Trainee Clinical Psychologist within NHSGGC. The research was conducted as part of the researcher's Doctorate in Clinical Psychology.

The researcher's clinical experience predominantly lies within Older People's Mental Health (OPMH) services, which provided a foundational understanding of the specific needs of this population. This familiarity may have influenced how they interpreted participants' experiences of discharge, potentially leading to a focus on narratives that align with clinical experiences or established psychological theories. The researcher had not worked specifically within OPMH inpatient settings, thus 'outsider' status provided a degree of subjectivity and an opportunity to approach data collection and analysis with curiosity. Additionally, the researcher identifies as an 'outsider' in terms of not being an older adult who has experienced psychiatric hospital admission. However they have personal experience as a close family member of someone who has undergone this experience, which may have shaped their emotional engagement with the research topic and introduced biases, such as overidentifying with certain narratives or emphasizing emotional aspects over other dimensions of the participants' experiences.

To mitigate these influences, minimise bias and ensure the research remained grounded in participants' perspectives, several strategies were employed by the researcher, including maintaining a reflective journal to regularly document and critically reflect on their biases, assumptions and emotional responses. This was further complemented by regular research and peer supervision, as well as two researchers independently coding three interview transcripts. A commitment to reflexivity guided the analysis, with particular attention on avoiding over-reliance on preconceived ideas and remaining open to the full range of participant experiences.

RESULTS

RMN FOCUS GROUPS

No RMN's were interviewed for this study. Three suitable participants expressed an interest in further information, but they did not opt-in to the study. They explained that this was due to an inability to take time away from clinical work to participate, due to staff shortages. Additional dates were offered, however no RMNs opted in to these focus groups and two of the interested potential participants unfortunately responded after the data collection phase was complete.

PATIENT INTERVIEWS

Seven patient participants were interviewed for this study. The researcher was made aware of seventeen eligible participants that had been contacted by their clinician regarding the study. Of these, 10 expressed an interest in participating and consented to further contact from the researcher. Of these, two declined participation, thus, eight participants opted in to participate. Due to unforeseen circumstances, one interview did not take place and the participant opted out of the study. Thus, seven participants were interviewed for this study. The mean age of participants was 71 years. The length of admission ranged from 8 weeks to 6 months. Participant characteristics are provided in Table 2.1. All participants were White Scottish or British. All participants opted for face-to-face interviews in a clinic space of their choice. Two participants opted to have a family member present during the interview.

Table 2.1.

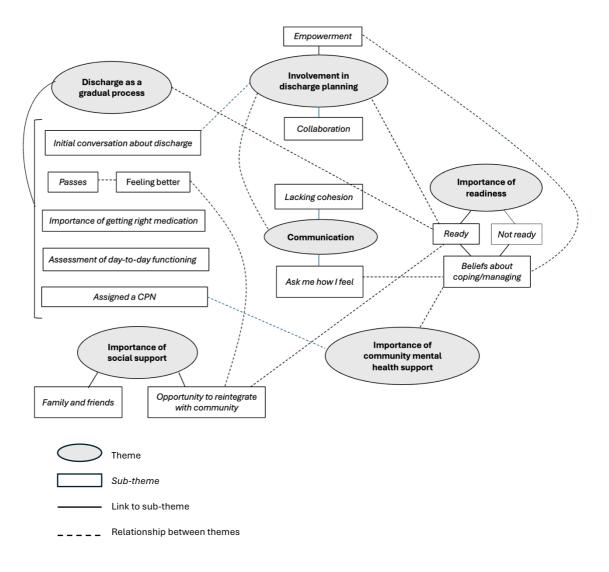
Participant characteristics

| Participant psuedonym | Age | Length of admission | Time since discharge |
|-----------------------|-----|---------------------|----------------------|
| Sam | 75 | 8 weeks | 4 months |
| Alice | 71 | 3.5 months | 5 weeks |
| Evelyn | 79 | 5 months | 5 months |
| Charlie | 70 | 6 months | 5 months |
| Betty | 66 | 3.5 months | 2 months |
| Jane | 68 | 5 months | 11 months |
| Rowan | 69 | 4.5 months | 6 months |

Six main themes were identified from the data: discharge as a gradual process; involvement in discharge planning; communication; social support; importance of community mental health support and importance of readiness for discharge. A number of sub-themes were identified within each main theme and they are presented in Figure 2.1. Thematic map.

Figure 2.1.

Thematic map



Discharge as a gradual process

Participants described discharge as a gradual process, something that was worked on and built up, and gradualness of this process was perceived positively by those that experienced it this way:

"They worked it up... They don't just say 'Right, you'll go home tomorrow', they gradually work at it, which is a good thing, I think." Alice

Participants spoke of their experiences of four main aspects to this gradual process.

Subtheme: Initial conversation about discharge

Most participants were able to recall when discharge was first mentioned to them, although not all could recall at what point in their admission this conversation first took place. Three of the participants reported that discharge was first mentioned to them by their psychiatrist. One reported that their psychiatrist provided reassurance that they would be discharged soon and could recall their memory of what the psychiatrist said:

"He says 'Don't you worry' … 'We'll have you out, soon as. You won't be in here for a long time. You just keep doing as you're doing'" Sam

Another participant reported that a conversation about discharge was initiated by their psychiatrist asking them how they felt about going home. Three of the participants reported that they were the ones who initiated conversations with their psychiatrist about discharge:

"I mentioned it and at the time I did, I wasn't there very long." Betty Some participants reported that the first time discharge was mentioned to them, by a health professional, was nurses implying they would be going home soon:

"It was just the nurses just used to say I could be getting home soon. You know, that was all, you know, they would sort of say to me 'You'll be getting home soon" Evelyn

One participant reported that whilst nurses implied that they would be discharged soon, they were not told by anyone in "authority" (the participant clarified that senior nurses and doctors were the clinicians with authority). They reported that this was different to their experience of discharge in their previous admissions to the same ward:

"Well actually, this last time, it was very strange because some of the nurses

would say 'Oh well, you'll be getting out soon'. And nobody in authority ever told me." Rowan

Subtheme: Passes and feeling better

All participants spoke of 'passes' (temporary leave from the ward) as part of that gradual process. Participants reported that the time spent out on pass increased throughout their admission and the time and frequency at which this increased was reported as different for each participant:

"They would take me out for a couple of hours, to the flat [apartment]. And then that built up – I ended up getting out overnight." Alice "But it was good what they done. You get your day passes and then your overnight stays, to build that relationship up with the new house." Jane Passes were seen by participants as something to help prepare them for discharge. One participant described passes as:

"...a way of introducing you to the outside world." Rowan

There was a sense that there was a causal relationship between an increase in time on passes and feeling better. However, that causality appeared to be experienced differently amongst participants. Some participants felt that the time out on, and frequency of, passes increased because they felt better. Whereas, others felt that this increase of time out on, and frequency of passes, led to them feeling better. One participant reported feeling that they would have benefited from a more 'built up' approach to discharge:

"So I think if I had the longer stretch of that ... if I had the same as the other guys, maybe for about two months - I was getting out every second week or every week - it would have built me up more ready for coming home... I think I'd They described witnessing other patients going out on passes for a longer stretch of time and at a higher frequency. Reflecting on this, they felt that going out on pass earlier into their admission, and for a longer time period, would have increased feelings of readiness for discharge and made their discharge an easier experience.

Subtheme: The importance of getting the correct medication

Most participants spoke of the influence of medication on the way that they felt, thought and experienced their discharge. One participant felt that the effectiveness of medication positively impacted their thinking style and made their experience in hospital easier:

"I'm finding that the tablets are working for me, you know. I think it made it a lot easier and the way I was feeling and my thoughts - my thoughts were always good. I just kept thinking positive all the time." Sam

Another participant spoke of the influence the dosage of their medication had:

"But the second time they put me on a dosage and things just settled down." Alice

They spoke of being discharged from hospital twice within the same care episode. They reported that their first discharge was unsuccessful and they were readmitted. They felt that when put on a different dosage of medication, the second time they were admitted, things settled down for them and they associated this with remaining out of hospital. One participant spoke of their psychiatrist cross titrating their medication:

"I think it was a combination ... He wanted to try Venlafaxine, so he done what was called a cross titration. And whilst seeing the psychologist and him doing that - I think once that was in place and then psychology was enabling me to understand "Look its early days. You have to give it time" ... So it did start to fall into place gradually." Betty

They spoke of the impact of this, alongside input from the psychologist to enable understanding around the influence of time on the effectiveness of medication. It appeared that they felt a combination of medication and psychology input, led to things gradually improving and leading to their discharge.

Subtheme: Assessment of day-to-day functioning

"So part of the discharge was that the occupational therapist, she would come and watch me frying. And it was good because I went home, I done everything that I was supposed to." Sam

Participants talked positively of functional occupational therapy assessments as part of the discharge process. They spoke of being asked to make lunch whilst the occupational therapist observed and of visiting places in the local community. It appeared that participants recognised these functional assessments as a part of the discharge process. One participant spoke of their hesitancy about returning to their house and explained that they had started to discuss alternative living arrangements with their family. However, it appeared that the passes and visits home with the OT increased their confidence in their ability to manage at home and this led to more certainty about their want to return to their own house:

"So, the OT actually took me home twice before I left. One of times she asked me to make lunch... And then another time she took me to a café. That was fine as well. And then I started to feel quite good ... The fact that I'd made lunch and then I did it again ... That kind of made-up my mind that I wanted to go home."

Subtheme: Assigned a community psychiatric nurse (CPN)

All participants spoke of being assigned a CPN upon or after discharge. This appeared to be a key part of the discharge process for participants. Knowing that support would continue from hospital to the community appeared to contribute to this participant's confidence in how things would be once discharged:.

"Because seeing the help I was getting, I knew I would still be getting the help from the community team and that, when I was out... The support that I had was great. You just knew that things were going to be ok." Jane

There was value placed on having continuity of care and the assurance that they would not be left without support. This appeared gave them confidence in both the system and their own ability to cope with the transition. Some participants reported that their CPN attended within the week after their discharge and some reported that they experienced a delay being assigned a CPN. When participants experienced a delay being assigned a CPN, they spoke of the reassurance and plan provided by the OPCMHT, to contact the service if they require support in the meantime. This subtheme is intrinsically linked to the main theme of 'Importance of community mental health support'. Participants reports on the type of support received, and the impact this had, can be found in the description of this theme.

Involvement in discharge planning

A number of participants reported that they felt involved in planning and decisionmaking regarding their discharge. Sub-themes of 'empowerment' and 'collaboration' were also identified due to participants recalling what their psychiatrist said, and how they said it, during conversations about discharge. Collaborative working and a sense of empowerment appeared to coincide together for participants. Generally, participants reported feeling listened to:

"He listened to you, what decision you wanted rather than him dictating" Alice They also acknowledged that they were provided with choice and empowered to make their own decisions and trusted by clinicians in knowing how they feel about discharge:

"... it must be you that decides', he says. 'I'm here - to make suggestions to you. And if you feel that that's going too fast for you, we'll just take a step back and slow down.'" Sam

"He said 'You're the person that'll know. You'll know yourself." Sam Some participants stressed the importance of the discharge process being collaborative in nature, not feeling that it was something in which they had no agency. There was a sense that collaboration resulted in the participant trusting the clinical team:

"I think we worked in partnership and I had to be honest with them as much as they were honest with me." Betty

"We'll try this', in a lovely, relaxed – great feeling. I trusted him." Sam

One participant reported that they did not feel involved in discharge planning and highlighted the lack of communication from their care teams as being a problem during their admission. They thought this was the biggest contributor to their lack of involvement in their own care.

Communication

Most participants spoke about the line of communication they experienced with

hospital staff regarding their discharge. This tended to be reflective of their experience of communication throughout their time in hospital, not just in relation to discharge.

Subtheme: Lacking cohesion

For some participants, it appeared that they experienced communication, amongst hospital staff, the patient and family members, as lacking in cohesion. Although participants felt involved in decisions about their discharge, they did not always feel that they, or other relevant people, were informed of the plans for their passes or discharge. This appeared to lead to miscommunications and feelings of confusion:

"Sometimes I used to think what is going on here? How do they (nurses) know? And he's (psychiatrist) telling me something - you know, I just - a bit mixed up... It didn't seem to gel together... Maybe a wee bit lack of communication." Alice

One participant spoke of, what appeared to be, a miscommunication with a nurse regarding when they were to return from a pass:

"I went home on the Thursday and I came back on the Friday, and he went 'What are you back for? You're supposed to be - you could have stayed out till Monday'. But nobody told me. And I found out that a bit strange." Alice

Another participant spoke about there being a lack of communication from hospital staff to their family members, despite them requesting that their family be informed:

"And I said "would you make sure that my daughter knows how I am" ... None of the nurses had got in contact with my daughter... The communication wasn't good towards – for my daughter." Sam When discussing their experiences of a lack of communication, this participant referenced a poster of the 'Triangle of Care' which was up in the ward and stated:

"That is not happening." Sam

The Triangle of Care is based upon the core principles that carers, people who use services and professionals should work in equal partnership to promote safety, support recovery and sustain wellbeing (Carers Trust Scotland, 2019). It appeared that for this participant, the lack of communication impacted on the way in which all three parties could work in equal partnership to effectively support them.

One participant spoke about not knowing who to ask about passes, indicating they were not informed of the appropriate line of communication regarding this:

"I wondered how they always got out all the time. I know they had different doctors. And I didn't know who to ask." Charlie

Subtheme: Ask me how I feel

This subtheme was identified because some participants felt they would have benefitted from hospital staff providing an opportunity for them to communicate their feelings about readiness for discharge. One participant reflected on their experience and stated that if they were asked about how they felt about being discharged, they would have communicated their belief that they did not feel ready and would benefit from remaining in hospital:

"But I think if people ask me questions at the beginning when I got out, I could have said a lot more. You know, if somebody said to me – it was in my mind to say to them, but silly I didn't - ... 'How do you feel getting out now?' ... I think I would have said to them 'I think I should be in there for another month or two. It appeared that the participant was aware, at the time, of how they felt about being discharged but would have benefitted from someone initiating and facilitating a space for them to voice their concerns.

Another participant talked about the benefit of being encouraged to think about life after discharge, in their communication with their psychiatrist. This communication appeared to lead them to realising they were not ready for discharge:

"But he asked me questions like 'Do you feel ready? How would you manage? How would you do your babysitting of your grandchildren?'. He enabled me to think about life and I'd think well, I'm not ready." Betty

The same participant appeared to experience communication around discharge planning between their health professionals as effective:

"And obviously the psychologist was able to feed into that. she was able to speak to him and share information." Betty

Social Support

Participants talked about the type, and impact of, support they received from their family, friends, neighbours and community groups throughout the discharge process. There appeared to be a causal link between social support and a sense of reintegrating into their community.

One participant was able to express this to their daughter who was present during the interview:

"Because I couldn't have done that all myself without you. You've done all that. The talking and the tablets." "I probably would have been in there a lot longer, because I wouldn't have had anybody to really sort of stick up for me." Sam

They spoke of their daughter supporting them to resolve complications with accessing their medications on discharge. This participant felt that they would not have been able to resolve issues if it was not for their daughter. They also felt that they would have remained in hospital a lot longer without the advocacy of their family.

Another participant spoke about the inclusion of family and friends in their safety plan for extended passes from the ward:

"So if I get a longer spell and have a safe plan, have the right phone numbers, the right family members, had some close friends. I would know what to do." Betty

When speaking about, what they felt, made their discharge successful, they spoke about the importance of:

"Knowing that I had family, friends and there was a kind of plan from them about how they were gonna help." Jane

Some participants spoke about the support they received from neighbours. They reported feelings of apprehension and anxiety about seeing their neighbours prior to discharge. This appeared to be tied to a sense of shame and fear of judgement about having been in psychiatric hospital:

"I didn't want them to know where I've been - even though they say there's not, there is still a stigma being in a hospital like that." Alice

However, they went onto speak of the response they received from their neighbours upon returning home and how this disproved their initial fears:

"In fact one of my neighbours came to the door on Friday night and she said 'I

care." Alice

Another participant felt they needed to move house because their neighbours had witnessed the incident that led to their hospital admission:

"And my biggest barrier for going home was - my neighbours came to my rescue that day ... So I was really scared about that. I thought I need to move, I can't go back there." Betty

They explained that their psychologist helped them to create a plan to face and challenge this fear, by going to visit their neighbours during an extended pass from the ward:

"That's where psychology really helped me. We had a plan that I would go and see them - before I was discharged, when I was on the more extended pass."

They reported that doing so helped to change their whole perception of going home:

"And then the neighbour around the corner ... She was so delighted to see me and so that changed my whole perception of home." Betty

Participants also spoke of the support they received from friends once they had returned home. One participant spoke positively of the practical support offered by friends from religious group they attend:

"As soon as I got home, it was one of them says "I'll come and pick you up to take you to the meeting. I'll come and do this and do that. And that's all taken care of. You know, you don't even need to ask, they just offer. Which is very good." Evelyn

Another participant spoke positively of the support of a social group they attend, which appeared to be centred around mental health and wellbeing: *"I go to a social group and it quoted as 'It's OK to not be OK'. So that that has been a very good support."* Rowan

Importance of community-based mental health support

When asked about the support received after being discharged from hospital, all participants spoke of the support they received from their older people community mental health service (OPCMHT), particularly their CPN.

Some participants reflected on feelings of hesitancy about being assigned a CPN upon discharge, and this appeared to be related to their beliefs at that time that they did not require further mental health input:

"I kept saying 'I don't really need a nurse coming out'. But as I said, it was a good thing because it gives you a wee bit sort of reassurance that there's somebody there." Sam

The importance of knowing their CPN was at the other end of the phone was a shared experience for most participants. It appeared to provide them with reassurance and confidence that they would be sufficiently supported should they require it:

"I know she's at the other end of a phone if anything was wrong." Alice

All participants felt that they were sufficiently supported by their CPN post-discharge and spoke of a range of ways in which their CPN provides support. Facilitating an opportunity for the participant to talk and actively listening were forms of CPN support experienced and valued by a number of participants:

"She comes and she lets me talk. And she listens to me." Sam "It's just the way she talks to me. You know, as if she really cares. I know she does. I can tell." Evelyn

"She listens. That's the main thing. And she can always be very positive about

Participants also described what appeared to be a strength and goal-focused approach from their CPN and this was perceived positively:

"When they came they would speak about 'What have you done? Let's concentrate on what you have done and how well you've done it and what would you like to do." Jane

Importance of readiness for discharge

This final theme represents what appeared to be a relationship between participants' views on their readiness for discharge and how they felt after being discharged.

Subtheme: Beliefs about being able to cope/manage

Most participants reported a sense of worry before and about being discharged. This was commonly related to their beliefs about being able to manage and cope with everyday life, such as engaging in activities of daily living, as well as related to a fear of negative evaluation from others, about having been admitted to a psychiatric hospital, as discussed previously.

Some participants reported feeling ready to be discharged. They spoke of feelings of happiness and excitement on returning home and of their initial fears and beliefs being disproved:

"But when I saw the first friend, I found that really hard, but it went fine. My expectation of that wasn't how it turned out." Betty

There also appeared to be a sense of wanting to moving away from mental health services for these participants:

"I don't think I need anybody else, you know? I feel as if I'm just getting on with my life now." Sam

Some participants reported feeling that they were not ready for discharge, that they were discharged too early. These participants spoke of an increase in feelings of anxiety since being discharged, as well as fears of becoming unwell again:

"But when I got out, at the beginning, I was saying to myself, I wish I stayed in for a bit longer. I don't think I'm ready. I felt as if I wished I was back in hospital after about 3-4 months... I felt I was a legal alien. I just wanted to hide in the house." Charlie

The relationship between feelings of readiness and feelings post-discharge is represented well by one participants experience of being discharged twice. When speaking about the first time they were discharged, when they felt they were not ready, they reported that they had stopped eating and reported feeling a sense of blackness:

"I wasn't ready the first time. And I felt they should have maybe known that… Because I remember getting home and it was on the Monday, I just went - it was just like a blackness… And I stopped eating and I just went right downhill. You know, I couldn't cope." Evelyn

This contrasted to the way they spoke about how they felt the second time they were discharged, when they felt ready:

"I felt so much calmer than I did the first time... I just felt this is, this is where I should be." Evelyn

DISCUSSION

This study aimed to gain an insight into older people's experience of discharge and transition, by asking those discharged from the care of NHS Greater Glasgow & Clyde's older people functional mental health wards to the care of older people community mental heath services (OPCMHT). Through reflexive thematic analysis (RTA), we identified six common themes: discharge as a gradual process; involvement in discharge planning; communication; the importance of social support; the importance of community mental health support; and the importance of readiness for discharge. Several of the themes and sub-themes identified were intrinsically linked.

Consistent with Redding et al.'s (2017) findings is that discharge is perceived as a gradual process, involving preparatory measures throughout admission. Disparities in participants descriptions of the discharge process indicate inconsistencies in discharge planning which affect how patients feel pre- and post-discharge. Participants who reported feeling ready to be discharged, shared a perception of discharge as a gradual process and reported active involvement in discharge planning.

Findings suggest that how discharge is initially mentioned and subsequently discussed with patients affects their perception of involvement in discharge planning. Being empowered by clinicians, to make their own decisions and be trusted by clinicians in knowing how they feel about discharge, contributed to participants feeling involved in the process, as well as experiencing discharge planning as a collaborative process. These findings align with Rotter's (1954) theory of locus of control, where individuals believe they can influence their health outcomes through personal agency. This sense of involvement and collaboration with clinicians in discharge planning reflects a stronger internal locus of control. An internal locus of control, where participants felt they have control over their recovery and outcomes, appears to link to higher perceptions of coping ability and readiness for discharge. Conversely, a lack of involvement appeared to reinforce an external locus of control, undermining participants confidence in their ability to cope. This contributes to the findings of numerous studies that an empowering approach in mental healthcare has been linked to the process of psychiatric recovery (Fitzsimons & Fuller, 2002; Leamy et al., 2011) and highlights the importance of empowerment and collaborative practices in psychiatric discharge planning for older people.

Passes were a key factor identified in the discharge process and the increase of time out on and frequency of passes appeared to be intrinsically linked to 'feeling better'. These findings align with Bandura's (1997) self-efficacy theory, whereby passes serve as a mastery experience, providing opportunities to confront and manage fears about coping outside of the hospital environment. By managing anxiety and becoming more comfortable with community reintegration, participants appeared to experience an increase in self-efficacy, contributing to a stronger sense of readiness for discharge. This supports prior findings that self-efficacy plays a considerable role in psychiatric recovery (Mancini, 2007; Barakat et al., 2021; Abraham et al., 2014) and demonstrates preliminary findings that passes during psychiatric hospital admission are a practical tool for building self-efficacy among older adults.

Findings also highlight the positive impact of social support and connectedness in fostering a successful discharge and reintegration into communities, concordant with the principles of self-determination theory (Deci & Ryan, 1985). Social support, particularly from family members, fulfils the basic psychological need for relatedness, increasing a sense of connectedness and support during hospital admission and discharge. Family members were also seen as advocates and key to the resolution of issues related to discharge, enhancing feelings of competence by helping participants navigate a complex system and regain a sense of control over their lives.

Additionally, participants reported that both they and their family members experienced a lack of cohesive communication from clinicians regarding their discharge plans and, more generally, throughout psychiatric hospital admissions. Despite the promotion of the 'Triangle of Care' (Carers Trust Scotland, 2019) within these settings, miscommunication and a lack of communication was frequently experienced by patients and their families. This lack of clear and consistent information can be seen to undermine the psychological need for autonomy, as participants and their families felt uninformed and unable to make empowered decisions about care and discharge planning. Taken together with patient experience reports of older people accessing community mental health services (Fortuna et al., 2017; Wilberforce et al., 2018), findings strongly indicate that improving issues with communication should be key focus to address in OPMH clinical interventions and future research.

Consistent with findings in prior research within the adult population (Redding et al., 2017), is of the importance of having someone to talk to or visit in the immediate days post-discharge. In the current study, knowing support was available from the older people community mental health team was vital to all participants both pre- and post-discharge. There was value placed on having continuity of care and the assurance that they would not be left without support. Central to the support provided by CPN's was having an opportunity to talk, being listened to and being encouraged to take a strength and goal-focused approach to the transition from hospital to home.

There were several reasons why RTA was the chosen data analysis method for this study. Firstly, it is an easily accessible and theoretically flexible interpretative approach to qualitive data analysis. Identifying as less qualitatively experienced, the researcher was provided the opportunity to complete a robust analysis of data, yet present them in a way which is readily accessible to those who are not part of academic communities. This was felt a vital part in ensuring the usability and applicability of the results of this study. Secondly, in RTA the subjectivity of the researcher is not considered a threat to the study findings, nor a negative source of bias (Braun & Clarke, 2020). A main aim for the researcher was ensuring participants felt listened to and well-represented in the data and this was driven by both professional and personal experience, and the use of a reflexive approach promoted in-depth reflection of these motivations throughout the research process. Thirdly, RTA is well-suited to the exploration and understanding of patient experience because it allows for a flexible, in-depth, and nuanced exploration of complex and subjective phenomena. The emphasis on reflexivity, meaning-making, and detailed, descriptive outputs makes it particularly valuable for capturing the richness of patient experiences and informing improvements in healthcare practice and policy.

Crucially, this study highlights how patient experience research offers patients the opportunity to identify areas of inefficiencies and improvements in service development, from the stance of an expert by experience. In sharing their experiences, the participants in this study offer valuable insight into how NHS Scotland can improve the discharge planning and processes for older adults requiring psychiatric hospital admission.

LIMITATIONS

A significant limitation of this study is that we were unable to address two of our research questions relating to nursing staff perceptions of the patient experience of discharge. On reflection, researchers should have consulted with the RMN's in the project design, to increase opportunities for accessibility, availability and interest in participation.

Whilst this study had an apt sample size for a qualitative design, care must be taken in the transferability the findings. This was a homogenous sample of white Scottish or British participants, all of which had good family support and were able to travel to attend the interview. Only patients who were deemed cognitively able and well enough to participate were given information regarding the study. Patients with cognitive impairment or who were not sufficiently well might have a different experience. Additionally, this research was conducted within only one health board of NHS Scotland. The provision of care within NHS Scotland is changing and may vary across the country, therefore it is acknowledged that experiences might differ.

CLINICAL IMPLICATIONS

Care teams should ensure patients are supported to access time away from the ward, where safe to do so, and that they are involved in planning the time and frequency of which these increase. Findings indicate that patients would also benefit from being encouraged to discuss their feelings about, and fears for discharge, and utilise passes to as an opportunity to address and resolve concerns. Extra efforts should be made to ensure patients without family or friends are provided with opportunities to access both social support and advocacy during the discharge process. Findings also emphasize the importance of inpatient care teams adhering to the core principles set out in the Triangle of Care (Carers Trust Scotland, 2019) and ensuring that all relevant parties are informed of the discharge decisions and plans made.

IMPLICATIONS FOR FUTURE RESEARCH

Understanding a clinician perspective of the discharge process is an important area for future research and would provide valuable insights into: what procedures are in place to involve patients in planning and decision making regarding their discharge; how 'readiness' for discharge is assessed or determined; and potential barriers to cohesive communication within OPMH settings. The association between patient involvement and readiness, or the function of passes and readiness for discharge were not explored further in this study. Future research examining these concepts could provide useful information on reducing length of hospital stay and risk of re-admission for those admitted to OPMH settings. Additionally, further research exploring the experiences and needs of older adults without family or social support could provide useful information on how the needs of this population can be appropriately met during psychiatric admission and discharge.

CONCLUSION

To the best of our knowledge, this is the first study to have explored older people's experiences of being discharged from mental health hospital. Findings support prior research findings that discharge from psychiatric hospital is a gradual process and is dependent on a number of steps and factors. Factors that seemed particularly pertinent to older people include passes, patient involvement in discharge planning, social support and community mental health support. Patient feedback indicates a need for improving the cohesiveness of communication between patient, clinician and families/carers around discharge planning. Further research exploring clinician's

perspectives of discharge would provide further insight into discharge planning processes and procedures and identify barriers to patient involvement and cohesive communication.

REFERENCES

Abraham, K. M., Miller, C. J., Birgenheir, D. G., Lai, Z., & Kilbourne, A. M. (2014). Selfefficacy and quality of life among people with bipolar disorder. *The Journal of nervous and mental disease*, *202*(8), 583-588.

Bandura, A. (1997). Self-Efficacy: The Exercise of Control. New York: Freeman.

Barakat A, Blankers M, Cornelis JE, Lommerse NM, Beekman ATF, Dekker JJM. The effects of intensive home treatment on self-efficacy in patients recovering from a psychiatric crisis. Int J Ment Health Syst. 2021 Jan 6;15(1):1. doi: 10.1186/s13033-020-00426-y. PMID: 33407731; PMCID: PMC7789166.

Beebe, L. H. (2010). What community living problems do persons with schizophrenia report during periods of stability? *Perspectives in Psychiatric Care*, 46(1), 48-55. doi: 10.1111/j.1744-6163.2009.00237.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. http://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

Braun, V. & Clarke, V. (2019). Reflecting on Reflexive Thematic Analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597.

https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2022b). *Thematic analysis: A practical guide*. Sage.

Carers Trust Scotland. (2019). *Triangle of Care: A Guide to Best Practice in Mental Health Care in Scotland, Third Edition.* https://carers.org/downloads/resourcespdfs/triangle-of-care-scotland/triangle-of-care-a-guide-scotland.pdf

Chung, D., Ryan, C. J., Hadzi-Pavlovic, D., Singh, S. P., Stanton, C., & Large, M. M. (2017). Suicide rates after discharge from psychiatric facilities. *JAMA Psychiatry*, *74*(7), 694-702. <u>https://doi.org/10.1001/jamapsychiatry.2017.1044</u>

Deci, E. L., Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior*. New York: Plenum.

Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*, 3. https://doi.org/10.1136/bmjopen-2012-001570

Fitzsimons, S., & Fuller, R. (2002). Empowerment and its implications for clinical practice in mental health: A review. *Journal of Mental Health*, *11*(5), 481-499.

Fortuna, K., Lohman, M., Batsis, J., DiNapoli, E., DiMilia, P., Bruce, M., & Bartels, S. (2017). Patient experience with healthcare services among older adults with serious mental illness compared to the general older population. The *International Journal of Psychiatry in Medicine*, *52*(4-6), 381-398. doi: 10.1177/0091217417738936.

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *Br Dent J*, *204*, 291–295.

Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLoS ONE*, *15*(5),

e0232076. https://doi.org/10.1371/journal.pone.0232076

Hatfield, C., & Dening, T. (2011). Functional mental illness. In T. Dening & A. Milne (Eds.), *Mental health and care homes* (Oxford Academic, 1 Feb.

2013). https://doi.org/10.1093/med/9780199593637.003.0016

Krumholz, H.M. (2013). Post-hospital syndrome – a condition of generalized risk. *N* Engl J Med, 368(2), 100-102. DOI: 10.1056/NEJMp1212324

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. *British Journal of Psychiatry, 199*(6), 445-

452. https://doi.org/10.1192/bjp.bp.110.083733

Mancini, M. A. (2007). The Role of Self–efficacy in Recovery from Serious Psychiatric Disabilities: A Qualitative Study with Fifteen Psychiatric Survivors. *Qualitative Social Work, 6*(1), 49-74. <u>https://doi.org/10.1177/1473325007074166</u>

Meehan, J., Kapur, N., Hunt, I. M., Turnbull, P., Robinson, J., Bickley, H., Parsons, R., Flynn, S., Burns, J., Amos, T., Shaw, J., & Appleby, L. (2006). Suicide in mental health in-patients and within 3 months of discharge. *British Journal of Psychiatry, 188*(2), 129-134. <u>https://doi.org/10.1192/bjp.bp.104.007336</u>

National Academies of Sciences, Engineering and Medicine. (2020). *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System.* Washington, DC: The National Academies Press. <u>https://doi.org/10.17226/25663</u>

Osborn, D.P.J., Favarato, G., Lamb, D. et al. (2021). Readmission after discharge from acute mental healthcare among 231 988 people in England: cohort study exploring predictors of readmission including availability of acute day units in local areas. *BJPsych Open*, 7 (4). https://doi.org/10.1192/bjo.2021.961 Public Health Scotland. (2020). Delayed Discharges in NHS Scotland.

https://publichealthscotland.scot

Puschner, B., Steffen, S., Völker, K. A., Spitzer, C., Gaebel, W., Janssen, B., Klein, H. E., Spiessl, H., Steinert, T., Grempler, J., Muche, R., & Becker, T. (2011). Needs-oriented discharge planning for high utilisers of psychiatric services: Multicentre randomised controlled trial. *Epidemiology and Psychiatric Sciences, 20*(2), 181-

192. https://doi.org/10.1017/S2045796011000278

Redding, A., Maguire, N., Johnson, G., & Maguire, T. (2017). What is the lived experience of being discharged from a psychiatric inpatient stay? *Community Mental Health Journal*, 53, 568-577. https://doi.org/10.1007/s10597-017-0092-0

Rotter, J. B. (1954). *Social learning and clinical psychology*. Prentice-Hall, Inc. <u>https://doi.org/10.1037/10788-000</u>

Royal College of Psychiatrists. (2019). *Delivering the NHS Long-Term Plan's ambition of ageing well: Old age psychiatry as a vital resource*.

https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-agefr oa 06.pdf?sfvrsn=c19e3cab 10

Scottish Government. (2021). *Delivering the right care in the right setting*.

https://www.gov.scot/news/delivering-the-right-care-in-the-right-setting/

The Kings Fund. (2015). *Improving hospital discharge and intermediate care for older people*. <u>https://www.kingsfund.org.uk/blog/2015/10/improving-hospital-discharge-</u> and-intermediate-care-older-people

The Mental Welfare Commission for Scotland. (2019). *The views of people with lived experience on the purpose of a psychiatric hospital*.

09/20190725 PurposeOfHospital.pdf

APPENDICES

Appendix 1.1 PRISMA 2020 Checklist

| Section and Topic | ltem # | Checklist item | Location where item is reported (page no.) | | |
|-------------------------|---|--|---|--|--|
| TITLE | - | | | | |
| Title | 1 | Identify the report as a systematic review. | 4 | | |
| ABSTRACT | r | | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | 5 | | |
| INTRODUCTION | | | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | 9 | | |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | 9 | | |
| METHODS | | | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | 9-10 | | |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | 9-13 | | |
| Search strategy | 7 | Present the full search strategies for all databases, registers and websites, including any filters and limits used. | 9-14 & Appendix 1.2 | | |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | 12-13 | | |
| Data collection process | ata collection 9 Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked | | | | |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | 10-13 | | |
| | 10b | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | 10-13 | | |
| Study risk of bias | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed | /Quality assessment | | |

| Section and Topic | ltem # | Checklist item | Location where item is reported (page no.) | | | | | | | |
|----------------------------------|---|--|---|--|--|--|--|--|--|--|
| assessment | | each study and whether they worked independently, and if applicable, details of automation tools used in the process. | 12 | | | | | | | |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results. | n/a | | | | | | | |
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | | | | | | | | |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data on conversions. | | | | | | | | |
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | n/a | | | | | | | |
| | 13d | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | | | | | | | | |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression). | n/a | | | | | | | |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesized results. | n/a | | | | | | | |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | n/a | | | | | | | |
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | n/a | | | | | | | |
| RESULTS | | | | | | | | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | 14 | | | | | | | |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | 14 | | | | | | | |
| Study characteristics | 17 | Cite each included study and present its characteristics. | 13-14 | | | | | | | |
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | /Quality assessment 25 | | | | | | | |
| Results of individual studies | 19 For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | | | | | | | | | |
| Results of | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. | 15-19 | | | | | | | |
| syntheses | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | n/a | | | | | | | |

| Section and Topic | ltem # | Checklist item | Location where item is reported (page no.) | | | | |
|--|-----------|--|---|--|--|--|--|
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | 15 | | | | |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. | n/a | | | | |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | n/a | | | | |
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | n/a | | | | |
| DISCUSSION | - | | | | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | 29-31 | | | | |
| | 23b | Discuss any limitations of the evidence included in the review. | 29-33 | | | | |
| | 23c | Discuss any limitations of the review processes used. | 31-33 | | | | |
| | 23d | Discuss implications of the results for practice, policy, and future research. | 32-33 | | | | |
| OTHER INFORMA | TION | | | | | | |
| Registration and | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | | | | | |
| protocol | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | | | | | |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | | | | | |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | | | | | |
| Competing interests | 26 | Declare any competing interests of review authors. | | | | | |
| Availability of data, code and other materials | 27 | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | | | | | |

| Component 1 | "patient satisfaction" OR "consumer satisfaction" OR "consumer expectations" OR "client satisfaction" OR "patient\$ experience\$" OR "patient reported" OR "patient reported experience" OR "patient reported experience" OR "PREM\$" OR "carer\$ satisfaction" OR "carer\$ experience\$" OR "carer reported" OR "carer reported experience" | | | | | | | |
|-------------|---|--|--|--|--|--|--|--|
| | AND | | | | | | | |
| Component 2 | "psychiatry"[Mesh] OR "psych*" OR "mental" OR "healthcare" OR "health care" OR "care" OR "Mental Health"[Mesh] OR "Mental Health Services"[Mesh]) OR "psychogeriatric\$" | | | | | | | |
| AND | | | | | | | | |
| Component 3 | "geriatric*" OR "older adult\$" OR "older people\$" OR "older people's" OR "elderly" OR "elderly people" OR "older patient\$" OR "elderly patient\$" OR "older resident\$" OR "elderly resident\$ | | | | | | | |
| | AND | | | | | | | |
| Component 4 | "tool*" OR "instrument*" OR "score*" OR "scale*" OR "survey*" OR "questionnaire*" OR "measure*" | | | | | | | |
| | AND | | | | | | | |
| Component 5 | development" OR "validation" OR "psychometric" OR "psychometrics"[Mesh] | | | | | | | |
| | | | | | | | | |

| Instrument development properties | Definition | Quality Criteria |
|---|--|---|
| Pre-study hypothesis and intended population | Specification of the hypothesis pre- study and if the intended population have been studied | √√ - Clear statement of aims and target population, as well as intended population being studied in adequate depth √ - Only one of the above or generic sample studied X- Neither reported |
| Actual content area (face validity) | Extent to which the content meets the pre-study aims and population | √√- Content appears relevant to the intended population √- Some relevant content areas missing X- Content area irrelevant to the intended population |
| Item identification | Items selected are relevant to the target population | √√- Evidence of consultation with patients, stakeholders and experts (through focus groups/one-to-one interview) and review of literature √- Some evidence of consultation X- Patients not involved in item identification |
| Item selection | Determining of final items to include in the instrument | √- Rasch or factor analysis employed, missing items and floor/ceiling effects taken into consideration. Statistical justification for removal of items √- Some evidence of above analysis X- Nil reported |
| Unidimenstionality | Demonstration that all items fit within an underlying construct | √- Rasch analysis or factor loading for each construct. Factor loadings >0.4 for all items √- Cronbach's alpha used to determine correlation with other items in instrument. Value >0.7 and <0.9 X- Nil reported |
| Response scale | Scale used to complete the measure | $\checkmark \checkmark$ - Response scale noted and adequate justification given \checkmark - Response scale with no justification for selection X- Nil reported |
| Instrument performance properties | | |
| Convergent validity | Assessment of the degree of correlation with a related measure | √√- Tested against appropriate measure, Pearson's correlation coefficient between 0.3 and 0.9 √- Inappropriate measure, but coefficient between 0.3 and 0.9 X- Nil reported or tested and correlates <0.3 or >0.9 |
| Discriminant validity | Degree to which an instrument diverges from another instrument that it should not be similar to | √√ - Tested against appropriate measure, Pearson's correlation coefficient <0.3 √ - Inappropriate measure, but coefficient <0.3 X- Nil reported or tested and correlates >0.3 |
| Predictive validity | Ability for a measure to predict a future event | √√ - Tested against appropriate measure and coefficient >0.3 √ - Inappropriate measure but coefficient >0.3 X- Nil reported or tested and correlates <0.3 |
| Test-retest reliability | Statistical technique used to estimate components of measurement error by testing comparability between two applications of the same test at different time points | $\sqrt{\sqrt{-}}$ Pearson's r value or ICC >0.8 $\sqrt{-}$ Measured but Pearson's r value or ICC <0.8 X- Nil reported |

 $\checkmark \checkmark$ - Discussion of responsiveness and change over time. Score changes > MID over time \checkmark - Some discussion but no measure of MID X- Nil reported

Notes: $\sqrt{\sqrt{-positive rating}}$, $\sqrt{-acceptable rating}$, X-negative rating. **Abbreviations:** ICC, intraclass coefficient; MID, minimally important difference.

| Scale name | Reference | Country | Purpose of scale | Sample | Admini- stration method | No. of items | Time frame | Response Scale | Dimensions/factors | Viewpoints and sources for item development |
|---|--|---------|---|--|-------------------------------|-----------------|----------------------------|---|--|---|
| Age-Friendliness Questionnaire (AFQ) | Wright, Fulmer & Boult (2021) | USA | Measure patients experience of the "age-friendliness" of healthcare | 1,632 older (65+) outpatients of geriatrics consult clinic and primary care providers | Self | 5 | Not specified | 5 point Likert (never to always) | Medications What matters Mobility Mentation | Healthcare professionals, quality improvement experts, and a patient-caregiver focus group |
| Person-centre Community Care Inventory (PERCCI) | Wilberforce et al. (2018) | UK | Measure of person- centredness to evaluate older people's experiences of community mental health and social care. | 596 older (65+) outpatients accessing integrated older people community mental health and social care services | Self | 18 | Not specified | 4 point Likert (never to always) | Interpersonal aspects Service aspects Reverse-scored items | Concept mapping focus groups with OP accessing voluntary sector providers of mental health services Patient and carer advisory group |
| Patient experiences in psychiatric departments for the elderly (PEPDE) | Ruud, Fjellestad & Hanssen- Bauer (2023) | Norway | Measure of patient experiences of psychiatric inpatient departments for the elderly | 96 elderly (65+) psychiatric inpatients | Self | 20 | Upon or after discharge | Varied 5 point likert for 17 items Dichotomous reponse scale for 3 | Patient-centred interactions Outcomes Care and safety Information on rights | Patient feedback from pilot Clinician and health worker advisory group |

Appendix 1.4 Further characteristics of included instruments

| | | | | | | | | | | 92 |
|--|------------------------------|-----------------|--|--|---------------------|----|--------------------------------------|--|--|--|
| Patient Assessme nt of Integrated Elde rly Care (PAIEC) | Uittenbroek et al. (2016) | Netherla nds | Assess the quality of integrated care from the perspective of elderly people | 223 elderly (75+) patients receiving integrated care and support due to frailty or complex care needs | Self | 20 | Post- intervention (12 months) | 5 point Likert (never to always) | Patient activation and contextual information Goal-setting and problem solving Coordination and follow up | Adaption of the PACIC by experts in elderly care Patient feedback |
| Partners at Care Transitions Measure (PACT- M) | Oikonomou et al. (2020) | UK | Assess the experience, quality and safety of care transitions from hospital to home in older patients | 138 older (65+) patients discharged from hospital | Self or clinican | 8 | Post- discharge | 5 point Likert (strongly disagree – strongly agree) | Patient involvement Medication management Discharge arrangements Coordination with other providers Providing information and guidance to patient/family Providing psychological and social support Anticipation and preparation for emergencies/deterioration Feelings of safety | Literature review, preparatory qualitative interview study with older people and their families, PPI advisory groups Delphi process with experts in patient involvement, patient safety and transitions |
| Intermediate care PREMs (IC-PREM) Home (and reablement) Based Patient Reported Experience Measure | Teale & Young (2015) | UK | Evaluate user experience of home- based intermediate care (IC) services | 627 users of home- based services Older people but age not specified | Self | 12 | At discharge | Varied | Staff have sufficient information Aware of goals Involvement in goal setting Aware of how to contact staff Questions answered Confidence in staff Involved in decisions about discharge Information provided for family Requirement for additional equipment discussed | Delphi consensus with panel of IC experts; IC practitioners; patient and public group; representation from Picker institute |

| | | | | | | | | | | 93 |
|--|-------------------------|-----------------|--|---|------|---|----------------------------|--------|--|---|
| | | | | | | | | | Discussion regarding further services after discharge Treated with dignity and respect | |
| Bed-Based Patient Reported Experience Measure | Teale & Young (2015) | UK | Evaluate user experience of bed- based intermediate care services | 1,832 users of bed- based services (social care re- ablement and healthcare hospital- at-home ser- vices) Older people but age not specified | Self | 8 | At discharge | Varied | Staff have sufficient information Involvement in goal setting Questions answered Confidence in staff Involved in discharge decisions Home circumstances considered Information provided for family Treated with dignity | Delphi consensus with panel of IC experts; IC practitioners; patient and public group; representation from Picker institute |
| The CareWell in Hospital (CWH) questionnaire | Bakker et al. (2014) | Netherla nds | Assess experiences of frail elderly inpatients in the provision of individualized, integrated care | 470 frail and non- frail medical, surgical and geriatric inpatients (70+) | Self | 8 | Upon or after discharge | Varied | Sufficiently informed regarding treatment options Treatment and care preferences discussed Co-decide regarding important issues Supported in finding (social) activities Knows relevant person for questions, problems, complaints Discussed post-discharge care needs Hospital informed other important people/providers of discharge Adverse events during hospital admission | Delphi process with elderly care representatives |

| | | | | | | | | | | 94 |
|--|-------------------------------------|--------|--|---|----------|----|---------------|----------------|--|--|
| Questionnaire concerning patient relatives' perception of the quality of geriatric care | Verho & Arnetz (2003) | Sweden | Measure patient relatives' perception of quality of geriatric care | 318 relatives of patients receiving community geriatric care 38 relatives of elderly inpatients Age not specified | Relative | 8 | Not specified | 4-point Likert | Information Nursing staff Caring processes Activity Contact Social support Participation Work environment | Structured interviews and focus group with patients relatives Pilot study |
| Case management quality questionnaire (CMQQ) | Hadjistavropoulo s et al. (2003) | Canada | Assess elderly client perceptions of the quality of community case management | 174 home care (HC) clients (50+) who had been case managed while in receipt of HC services and 78 long-term care (LTC) clients who were case managed prior to admission to LTC | Self | 30 | Not specified | 5-point Likert | Accessibility Efficiency Assessment/coordination skills | Focus groups and key informant interviews with HC or LTC care clients and their family members |
| Sinclair Compassion Questionnaire (SCQ) | Sinclair et al. (2021) | Canada | Measure patient experiences of compassion in healthcare | 633 participants (mean age = 74) living with a life- limiting illness recruited from acute, home and long-term care settings and a hospice. | Self | 15 | Not specified | 5-point Likert | Domains of the Patient Compassion Model: Feel cared for Genuine concern Attentive Provided comfort Very supportive Provided care Spoke with kindness Saw as person Behaved in caring way Really understood needs Good relationship See my perspective Warm presence Sincere | Qualitative interviews with patients Focus groups with HCP, educators and administrators Delphi process with international subject matter experts and patient advisors, along with cognitive interviews with patients. |

| | | | | | | | | | | 95 |
|---|--------------------------|--------|---|---|---------------|----|-------------------------|---|--|--|
| User reported measure of care co-ordination | Crump et al. (2017) | UK | Capture perceptions of care coordination in older service users with one or more chronic conditions | 562 older (65+) people with at least one chronic condition | Sel | 46 | Not specified | Varied | Management continuity Information continuity Relational continuity | Stakeholder consultation Target audience focus groups and cognitive testing |
| Family Inpatient Comms Survey (FICS) | Torke, et al. (2017) | US | Measure communication experiences of surrogates of older adults in the acute hospital setting | 350 surrogates of hospitalized older (65+) adults | Surrogat e | 30 | During hospital stay | 5-point Likert (strongly agree to strongly disagree) | Information Emotional support | Surrogate interviews Expert review Pilot testing using cognitive interviewing |
| Quick FICS-5 Quick FICS-10 | Burke et al. (2023) | US | Measure communication experiences of surrogates of older adults in the acute hospital setting | 364 surrogates of hospitalized older (65+) adults | Surrogat e | 5 | During hospital stay | 5-point Likert (strongly agree to strongly disagree) | Information Emotional Support | n/a |
| Patient perspective on care and rehabilitation (PaPeR) | Wressle et al. (2006) | Sweden | Evaluate the patients perspective on geriatric care and rehabilitation | 221 older people (m= 79) recently discharged from geriatric inpatients | Intervie w | 19 | Post- discharge | 5-point Likert (totally agree to totally disagree) | Respect and safety Information and participation Rehabilitation interventions | Key informant interviews Literature review Expert panel consultation |
| Person-centered Climate Questionnaire - Patient (PCQ-P) <i>LTC validation</i> | Yoon et al. (2015) | US | Measure person- centred care from the perspective of elder nursing home residents | 189 older (m = 79.5) nursing home residents | Self | 17 | Not specified | 6-point Likert | A climate of: 1. Hospitality 2. Safety 3. Everydayness | |

| | | | | | | | | | | 96 |
|---|---------------------------|-----------------------|--|---|-------------------|----|-------------------------|--|--|--|
| Elderly resident- perceived caring scale (EPCS) | Hwang et al. (2012) | Taiwan | Measuring the caring in nurses perceived by elderly residents of long-term care facilities (LTCFs) | 297 elderly (60+) LTCF residents | Intervie w | 14 | Not specified | 5-point likert (absolutely agree to absolutely disagree) | Comforting Encouraging | Literature review Delphi study with experts and elderly laypersons |
| Thriving of Older People Assessment Scale (TOPAS) | Bergland et al. (2015) | Norway & Sweden | Measure LTCF resident experiences of thriving | 259 residents (m = 86), 146 family members and 52 staff from LTCF | Self and proxy | 32 | Not specified | 6-point Likert (disagree completely to agree completely) | Resident attitudes Quality of care and caregivers Engagement and relationships Keeping in touch with places and people of importance Physical environment | Literature reviews Qualitative interviews with target audience |
| Empowerment Questionnaire for Inpatients (EQuIP) | Lopez et al. (2010) | UK | Measures levels of empowerment experienced by older adults admitted to a psychiatric ward | 87 older (65+) inpatients with a functional psychiatric diagnosis | Self | 16 | During hospital stay | 4-point Likert | Information Choice Communication | Triangulation method Expert consultation (delphi) Clinical staff survey Focus groups with inpatients |
| Program for All- Inclusive Care of the Elderly (PACE) Satisfaction Survey | Atherly et al. (2004) | US | Measuring the satisfaction of older persons and their family members with capitated care | 165 frail older (age not specified) adults 137 relatives | Self and proxy | 23 | Not specified | 5-point Likert | Percieved 1. Access to medical care 2. Technical quality of medical care 3. Interpersonal quality 4. Decision making | Literature review Expert consultation |
| Older Adult Experience Survey | Gilsenan et al. (2021) | Canada | Measure the experience of older adults in appointment-based specialised geriatric services. | 131 frail older adults with complex medical, functional, and psychosocial issues. | Self | 12 | Not specified | Varied | Access Interpersonal Communication Continuity and coordination Comprehensiveness of services Trust Patient-reported impacts of care | Literature review Delphi process Cognitive interviews with target population Pilot study Patient feedback |



West of Scotland Research Ethics Service

Dr David Grinter Lecturer / Academic Supervisor University of Glasgow Clarice Pears Building School of Health & Wellbeing, University of Glasgow 90 Byres Road G12 8TB



West of Scotland REC 4 Research Ethics Ward 11, Dykebar Hospital Grahamston Road Paisley PA2 7DE

Date22 February 2024Direct line0141 314 0213E-mailWoSREC4@ggc.scot.nhs.uk

Dear Dr Grinter

 Study title:
 Older people's experience of discharge from mental health inpatient settings: a qualitative exploration of patient and nurse perspectives

 REC reference:
 24/WS/0003

 IRAS project ID:
 330114

Thank you for your letter of 06 February 2024, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The <u>UK Policy Framework for Health and Social Care Research</u> sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of <u>research transparency</u>:

- 1. registering research studies
- 2. reporting results
- 3. informing participants
- 4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- · clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a <u>minimal record</u> on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform <u>deferrals@hra.nhs.uk</u> and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, <u>a minimum research summary</u> will still be published in <u>the research summaries database</u>. At the end of the deferral period, we will publish the <u>full research summary</u>.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: <u>Research summaries - Health Research Authority (hra.nhs.uk)</u>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at <u>Managing your approval - Health Research</u> <u>Authority (hra.nhs.uk)</u>

Ethical review of research sites (as applicable)

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|--|---------|-------------------|
| Copies of materials calling attention of potential participants to the research [Ward manager email] | 1 | 10 November 2023 |
| Copies of materials calling attention of potential participants to the research [Clinician recruitment email] | 4 | 29 January 2024 |
| Covering letter on headed paper [REC amendments cover letter] | 2 | 06 February 2024 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) | | 14 July 2023 |
| GP/consultant information sheets or letters [Clinician Letter] | 4 | 02 February 2024 |
| Interview schedules or topic guides for participants [Patient] | 4 | 10 November 2023 |
| Interview schedules or topic guides for participants [Staff] | 3 | 10 November 2023 |
| IRAS Application Form [IRAS_Form_05122023] | | 05 December 2023 |
| Letters of invitation to participant [Staff invite email] | 1 | 10 November 2023 |
| Participant consent form [Focus Group] | 5 | 06 February 2024 |
| Participant consent form [Patient Interview] | 5 | 02 February 2024 |
| Participant information sheet (PIS) [Staff - Whistle blowing Guide] | 1 | 29 January 2024 |
| Participant information sheet (PIS) [Patient post interview support] | 1 | 29 January 2024 |
| Participant information sheet (PIS) [Staff] | 4 | 06 February 2024 |
| Participant information sheet (PIS) [Patient] | 5 | 02 February 2024 |
| Research protocol or project proposal [Protocol] | 6 | 06 February 2024 |
| Summary CV for Chief Investigator (CI) [CI CV] | | 31 March 2022 |
| Summary CV for student | | 07 September 2023 |
| Summary CV for supervisor (student research) | | 31 March 2022 |
| Summary CV for supervisor (student research) [Supervisor GCP certificate] | | 09 January 2024 |
| Summary, synopsis or diagram (flowchart) of protocol in non-technical language | 1 | 10 November 2023 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <u>Quality assurance - Health Research Authority (hra.nhs.uk)</u>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities- see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 330114 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

| On behalf of Dr Michael Fail Chair | |
|--|---|
| Enclosures: | List of names and professions of members who were present at the meeting and those who submitted written comments |
| | After ethical review guidance for sponsors and investigators – <u>Non CTIMP Standard Conditions of Approval</u>] |
| Copy to: | Mrs Sinead Traynor Lead Nation Scotland: gram.nrspcc@nhs.scot |

West of Scotland REC 4

Attendance at Sub-Committee of the REC meeting

Committee Members:

| Name | Profession | Present | Notes |
|------------------------|--|---------|------------------|
| Dr Wendy Cohen | Speech & Language Therapist (Vice Chair) | Yes | Chair of Meeting |
| Dr Niamh Davies-Branch | Medical Registrar | Yes | |
| Mr Mitchell Grant | Student | Yes | |

Also in attendance:

| Name | Position (or reason for attending) |
|-----------------------------|------------------------------------|
| Mrs Abibat Adewumi-Ogunjobi | REC Manager |

Appendix 2.2 Board Approval letter



Research & Innovation

Grahamston Road Paisley, PA2 7DE Scotland, UK

Dykebar Hospital, Ward 11

Coordinator/administrator: Euan Rennie Telephone Number: E-Mail: euan.rennie@ggc.scot.nhs.uk Website: https://www.nhsggc.org.uk/aboutus/professional-support-sites/research-innovation

05/03/2024

Miss Georgia Smith NHS Greater Glasgow & Clyde

NHS GG&C Board Approval

Dear Ms Georgia Smith

| Study Title: | Older peoples experience of discharge from mental health inpatient settings: a qualitative |
|-------------------------|--|
| - | exploration of patient and nurse perspectives |
| Principal Investigator: | Miss Georgia Smith |
| GG&C HB site | NHS Greater Glasgow and Clyde |
| Sponsor | University of Glasgow / NHS GG&C |
| R&I reference: | UGN23MH365 |
| REC reference: | 24/WS/0003 |
| Protocol no: | V6 06.02.2024 |
| (including version and | |
| date) | |

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant Approval for the above study.

Conditions of Approval

- 1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file. Researchers must follow NHS GG&C local policies, including incident reporting.

- 2. For all studies the following information is required during their lifespan.
 - a. First study participant should be recruited within 30 days of approval date.
 - b. Recruitment Numbers on a monthly basis
 - c. Any change to local research team staff should be notified to R&I team
 - d. Any amendments Substantial or Non Substantial
 - e. Notification of Trial/study end including final recruitment figures

Page 1 of 2

letter



5

f. Final Report & Copies of Publications/Abstracts

g. You must work in accordance with the current NHS GG&C COVID19 guidelines and principles. Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Euan Rennie Research Co-ordinator

CC: Sinead Traynor

letter

Appendix 2.3 Interview consent form v.05 20.02

https://osf.io/k5rva/?view_only=9d881d8ecd6a468fa 248499a09814b44

Appendix 2.4 Patient PIS v.05 02.02

Appendix 2.5 OPCMHT clinician email v.04 29.01

Appendix 2.6 Patient interview schedule v.04 10.11

Appendix 2.7 Patient ppt post-interview support v.01 29.01

Appendix 2.8 Ward manager email v.01 10.11

Appendix 2.9 Staff invite email v.01 10.11

Appendix 2.10 Staff interview schedule v.03 10.11

Appendix 2.1 Focus group consent form v.05 06.02

Appendix 2.12 A 15-Point Checklist of Criteria for Good Thematic Analysis Process (Braun & Clarke, 2006)

<u>A 15-Point Checklist of Criteria for Good</u> <u>Thematic Analysis Process (Braun and</u> <u>Clarke, 2006)</u>

| Transcription | 1. | The data have been transcribed to an |
|---------------|-----|---|
| | | appropriate level of detail, and the |
| | | transcripts have been checked against the |
| | | tapes for 'accuracy'. |
| Coding | 2. | Each data item has been given equal |
| | | attention in the coding process. |
| | 3. | Themes have not been generated from a |
| | | few vivid examples (an anecdotal |
| | | approach) but, instead, the coding |
| | | process has been thorough, inclusive and |
| | | comprehensive. |
| | 4. | All relevant extracts for all each theme |
| | | have been collated. |
| | 5. | Themes have been checked against each |
| | | other and back to the original data set. |
| | 6. | Themes are internally coherent, |
| | | consistent, and distinctive. |
| Analysis | 7. | Data have been analysed rather than just |
| | | paraphrased or described. |
| | 8. | Analysis and data match each other – the |
| | | extracts illustrate the analytic claims. |
| | 9. | Analysis tells a convincing and well- |
| | | organised story about the data and topic. |
| | 10. | A good balance between analytic |
| | | narrative and illustrative extracts is |
| | | provided. |
| | | |

| Overall | 11. | Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly. |
|-------------------|-----|--|
| Written report | 12. | The assumptions about ThA are clearly explicated. |
| | 13. | There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent. |
| | 14. | The language and concepts used in the report are consistent with the epistemological position of the analysis. |
| | 15. | The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'. |

(Braun and Clark, 2006, p37)

Standards for Reporting Qualitative Research (SRQR)*

> http://www.equator-network.org/reportingguidelines/srqr/

Title and abstract

17

| | 42 |
|--|----|
| Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | |
| Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 46 |

Introduction

| | 48-51 |
|--|-------|
| Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | |
| Purpose or research question - Purpose of the study and specific objectives or questions | 51-52 |

Methods

| | 52-56 |
|---|-------|
| Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale** | |
| | 56-57 |
| Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | |
| Context - Setting/site and salient contextual factors; rationale** | 52-53 |
| Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale** | 52-53 |
| Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 52 |
| Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale** | 53-55 |

| | 1 |
|---|-------|
| Data collection instruments and technologies - Description of instruments (e.g., | 53-55 |
| interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | |
| | 53-55 |
| Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | |
| Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of | 53-56 |
| data integrity, data coding, and anonymization/de-identification of excerpts | |
| Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale** | 55-56 |
| Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale** | 56 |

Results/findings

| Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 57 |
|---|----|
| Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 57 |

Discussion

| Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 73 |
|---|----|
| Limitations - Trustworthiness and limitations of findings | 77 |

Other

| Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | |
|---|--|
| Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting | |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.00000000000388