



**A critical commentary that addresses the needs of
vulnerable populations in healthcare:
Evidence from mixed methods systematic reviews**

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Deborah Edwards

Summary

Background: Although vulnerable populations have been a focus in healthcare research for over 50 years, little research has been conducted that has explored the link between chronic illness and healthcare inequalities.

Aim: The aim of this critical commentary is to understand the needs, characteristics and situations that perpetuate health inequalities for vulnerable groups and to explore how health inequalities can be ameliorated.

Methodology: The published works contributing to this critical commentary are all mixed methods systematic reviews (MMSRs) which are a review type in the wider family of evidence synthesis. The vulnerable groups covered within this critical commentary include adults living with dementia; adults with physical disabilities; older adults who are physically frail; young people with a mental health condition; and adults at end of life with severe mental illness. A variety of issues were considered that affect these vulnerable populations while navigating the healthcare system upon accessing healthcare including admission and discharge or whilst experiencing care in the acute hospital setting. The vulnerable populations conceptual model (VPCM) was used to provide an organising framework in which I explored factors related to resource availability, relative risks, and health status.

Findings: From the wider literature we know that vulnerable populations can encounter substantial challenges navigating healthcare systems which can subsequently lead to delays in diagnosis, higher rates of morbidity and premature mortality. The majority of MMSRs have identified factors relating to resource availability which was conceptualised as interactions and/or relationships with healthcare professionals. This is of concern as the VPCM proposes that those who lack available resources are at increased risk of negative health outcomes leading to additional increase in societal costs and burden.

Conclusions: Using the VPCM in this way has potential value to inform healthcare practice, and policy about the opportunities and resources needed to protect the health status of vulnerable populations. It is crucial that healthcare professionals understand the unique challenges involved in caring for potentially vulnerable populations and that they take measures to improve the quality of their interactions so that equitable care and treatment can be provided.

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Abbreviations

AHRQ	Agency for Healthcare Research and Quality
ALM	Article-level metrics
CoCaDS	Challenges of Cancer and Disability Study
CIOMS	Council for International Organizations of Medical Sciences
CQC	Care Quality Commission
CYP	Children and young people
DORA	San Francisco Declaration on Research Assessment
EOL	End-of-life
EPPI-Centre	Evidence for Policy and Practice Information and Co-ordinating Centre
HCP	Healthcare professional
JBI	JBI Collaboration
KESS	Knowledge Economy Skills Studentship
MMSR	Mixed methods systematic review
MTF	Malnutrition Task Force
NHS	National Health Service
NIHR	National Institute of Health & Social Care Research
PHC	Preventative health care
PHE	Public Health England
PLWD	People living with dementia
SDH	Social determinants of health
SMD	Social model of disability
SMI	Severe mental illness
SR	Systematic review
UK	United Kingdom
VPCM	Vulnerable populations conceptual model
WHO	World Health Organization

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Chapter 1: Introduction

This PhD by published works¹ consists of six purposefully selected² international, peer-reviewed publications published between 2016 to 2021 ([appendix 2](#)), combined with a critical commentary. The “golden thread” for this critical commentary is vulnerable groups in healthcare. The aim of this critical commentary is to understand the needs, characteristics and situations that perpetuate health inequalities for vulnerable groups and to explore how health inequalities can be ameliorated.

Although vulnerable populations have been a focus in healthcare research for over 50 years (Flaskerud et al. 2002), little research has been conducted that has explored the link between chronic illness and healthcare inequalities (Grabovschi et al. 2013). Through this critical commentary I address this significant gap and provide a detailed understanding of the needs of key vulnerable populations and how they may not be met in many healthcare settings. I framed this work using a model of vulnerability, specifically the vulnerable populations conceptual model (VPCM) (Flaskerud and Winslow 1998). I show how the publications, make an original contribution to knowledge and facilitated my understanding of the factors that perpetuate health inequalities for vulnerable groups. In turn, it is envisaged that this work will contribute to improving healthcare professionals (HCPs) understanding of vulnerability.

The published works have formed a cohesive body of work in considering and illuminating a variety of issues that affect vulnerable populations³ as they navigate the healthcare system, either when accessing and moving through healthcare (**papers 1 and 2**), or whilst experiencing care in the acute hospital (**papers 5 and 6**) or inpatient mental healthcare setting (**papers 3 and 4**).

¹ Hereafter referred to throughout this commentary as thesis.

² From a body of work published between 2009 and 2022 ([appendix 1](#)).

³ The vulnerable populations that form part of this thesis as presented across the published works are presented on page 7.

The methodology underpinning this body of work draws on the discipline of evidence synthesis, defined by Gough et al. (2020, p. 2) as

The review of what is known from existing research using systematic and explicit methods in order to clarify the evidence base.

Evidence synthesis encompasses a broad range of review types, of which mixed methods systematic reviews (MMSRs) are one example. They are becoming increasingly important within evidence-based healthcare as they can offer a deeper understanding of findings from both qualitative and quantitative research. My published works are all MMSRs and in this critical commentary I show how my own advances in this methodology have been used to generate new knowledge, inform policy development and impact on practices/services.⁴ In utilising mixed methods evidence, I draw on the concepts of pragmatism which expresses that all knowledge is based on experience (epistemology) whilst at the same time acknowledging that the world is both socially constructed and real (ontology). Pragmatism has its roots in the work of American philosophers such as Dewey, Meade and James (Morgan 2007). Although I acknowledge that concerns have been raised over grounding mixed methods in pragmatism (Liu 2022), I agree with the work of Creswell and Garrett (2008, p. 327) and others who postulate that pragmatism in the context of mixed methods research is a way in which different methods can be used to answer a research question.

The aim of this critical commentary is to evaluate the contribution made by the published works to the advancement of the discipline. Specifically, to outline the key themes that give the works their defining coherence, to set the published works in the context of the existing literature, to demonstrate how the works make a comprehensive and original contribution to learning, to explain the choice of research methodologies and to describe my role in the multi-authored works.

This critical commentary is presented across five chapters. Chapter two presents the theory and some key tensions underpinning understandings of vulnerability, health inequalities and theories of vulnerability. Chapter three sets the findings from each published work in the context of the existing literature and makes a unique

⁴ See chapter 4, section 4.4, page 34 for the impact of the published works.

contribution to the knowledge base by placing the novel findings from each published work in the context of the VPCM. Chapter four provides a justification for the choice of research methodology including the contribution to knowledge development and impact, whilst conclusions are drawn in chapter five.

Chapter 2. Background and theoretical underpinnings

This chapter presents the background and theory underpinning understandings of vulnerability, health inequalities and theories of vulnerability including the VPCM.

2.1. Vulnerability

Although the term vulnerability is a general concept, the meaning has evolved and use of the term within healthcare is not consistently defined (Clark and Preto 2018; de Groot et al. 2019). The Department of Health (2000, pp. 8-9) define a vulnerable adult as:

A person aged 18 or over who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.

For children however, it is more difficult to define vulnerability given the breadth of the concept, as illustrated by the Children's Commissioner for England who developed seven categories of vulnerable children. Children in mental health institutions or other forms of hospital are included in one of these categories (Bright 2017).

As part of an in-depth analysis of national and international research ethics policies and guidelines, Bracken-Roche et al. (2017) found that in documents such as the Declaration of Helsinki (World Medical Association 2018) and the Council for International Organizations of Medical Sciences (CIOMS 2017), vulnerability is commonly described in terms of vulnerable groups. For example, Dixon-Woods et al. (2005) describes vulnerable groups as children, young and older people, while Spiers (2000) identifies older people, children, and people with chronic illness.

De Chesney (2019) in considering vulnerability in relation to healthcare issues frames vulnerability from two perspectives: firstly as a set of individual characteristics in which an individual is seen within a system context and secondly as an aggregate view of groups which is termed vulnerable populations. Providing extensive lists of the groups or populations that may be vulnerable is often termed categorical vulnerability (Gordon 2020). In her seminal work, Aday (1993) identified key

population groups⁵ who at the time were felt to be the most vulnerable to disease and injury in the United States, viewing vulnerability as an external judgement to an individual or group that may be susceptible to ill health (Aday 1993). This has been referred by Spiers (2000, pp. 7-8) as an “etic” perspective which conveys that vulnerability is the “susceptibility to harm”.

One of the criticisms of this categorical approach to vulnerability is that little consideration is given to the sources of vulnerability. However, vulnerability is not always described as a “dichotomous experience”, in which a person is seen as either vulnerable or not. In contrast, Heaslip and Ryden (2013, p. 10) propose that vulnerability should also be seen as being on a “dynamic continuum” and not solely a characteristic of the individual circumstances or the environment but as an interaction between the person and the environment. Additional concerns with the categorical approach proposed by Bracken-Roche et al. (2017) are firstly, that the categories of vulnerable populations can be too broad or too narrow and that secondly the importance of assessing an individual participant’s characteristics outside membership of the wider group can be neglected (Bracken-Roche et al. 2017).

Just framing vulnerability in terms of vulnerable populations is limited and through this critical commentary I will consider that vulnerability can also be thought of as being on a spectrum where a particular characteristic or situation has the potential to make a person more or less vulnerable and consequently at greater or lesser risk of harm (Gordon 2020). This approach first proposed by Rogers (1997) is termed situational (Rogers 1997) or contextual vulnerability (Gordon 2020) and ascertains that vulnerability is situational where a person who is not especially vulnerable in one environment may, however, feel extremely vulnerable in another. In a qualitative research study that explored how physicians classify someone as “vulnerable”, Sossauer et al. (2019) reported that vulnerability occurs in healthcare settings due to a gap between the person’s needs and the care provided. The authors inferred that

⁵ High risk mothers and infants, those who are chronically ill and disabled, persons living with HIV/AIDS, those with chronic mental health conditions, alcohol and substance abusers, those who are likely to commit suicide or murder, abusive families, homeless people, immigrants and refugees.

this is in part, a result of a mismatch between the person's individual characteristics and HCPs' perception (Sossauer et al. 2019).

This view of vulnerability can be used to understand how a person may feel when they enter the healthcare environment. Spiers (2000, p.716), describes this as an "emic" perspective which conveys a "state of being threatened and a feeling of fear of harm". Nevertheless, this is an aspect of vulnerability that is often neglected, and Bracken-Roche et al. (2017) in their analysis of national and international ethics guidance documents found that situational vulnerability is less prominently reported.

A broader perspective considered by some authors is one that places vulnerability as not only initiating ill-health but also impacting on prognosis, interfering with recovery and creating opportunities for care options to decrease the consequences of vulnerability. Drawing on this concept, De Groot et al. (2019) used a Delphi-like procedure with two independent panels of experts to agree on a definition and model of vulnerability that specifically relates to health and healthcare in developed countries. They define vulnerability as:

A dynamic state that reflects converging effects of a set of interacting and amplifying personal and environmental factors, which together increase an individual's susceptibility to ill health and which hampers the recovery process to normal health once ill health has occurred.
(de Groot et al. 2019, p. 12)

Four measurable components of vulnerability were identified: not having sufficient material⁶ components; a person not being and feeling able to take responsibility for their health; engaging in unhealthy or risk taking activities and behaviours; and not experiencing social support (de Groot et al. 2019). These findings build on the seminal work of Aday (1993) who proposed a framework for studying vulnerable populations that considers both the availability and distribution of community resources as well as individual characteristics. It is acknowledged that individuals at different times in their lives may be more or less at risk of poor health and that some individuals who are vulnerable are likely to be more at risk than others. Living with a long-term physical condition (being in poor physical health), for example, may also make one more vulnerable to (at risk of) poor psychological health which may result

⁶ The authors (de Groot et al. 2019) did not define material components but it can be assumed that they are referring to economic resources.

in fewer supportive social contacts (poor social health). Those who also have fewer material (economic) as well as non-material (psychological or social) resources to help during illness are likely to be at an increased risk of harm (Aday 1993).

In bringing together the published works that form part of this critical commentary I recognise that individuals with certain intrinsic characteristics are vulnerable populations. This includes adults with physical disabilities (**paper 1**), severe mental illness (SMI) (**paper 2**), young people with complex mental health needs (**papers 3 and 4**) and frail older adults (**paper 5**) and people living with dementia (PLWD) (**paper 6**). I explore further what it is that makes patients who are already vulnerable due to the inherent nature of their conditions, more or less vulnerable as they navigate the healthcare system (situational vulnerability), whilst at the same time acknowledging the interplay of environmental and healthcare resources.⁷

2.2. Health inequalities

Vulnerability, as well as being related to intrinsic categories such as those described above, is also related to being socially and structurally disadvantaged. As although the health outcomes experienced between groups and individuals in many instances can be attributed to chance, often they are influenced by a range of non-medical factors referred to as the social determinants of health (SDH). The World Health Organization (WHO) (2022, online) define the SDH as:

The non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.

Health inequalities⁸ and the SDH are also described as the systematic differences in health between different groups of people (Whitehead and Dahlgren 2007). After reviewing commonly used definitions for health inequalities, McCartney et al. (2019, p. 28) proposed the following definition:

Health inequalities are the systematic, avoidable and unfair differences in health outcomes that can be observed between populations, between social groups within the same population or as a gradient across a population ranked by social position

⁷ See chapter 3, page 15.

⁸ A number of different terms are used across the literature to describe health inequalities and include health inequity and health (care) disparities which are often interchangeably. In this thesis I use the term health inequalities, as it is the term commonly used within Europe (McCartney et al. 2019).

It has been conclusively shown that a wide range of factors influence health inequalities including socio-economic factors (for example, income), geography (for example, urban or rural region), specific characteristics (for example, sex, ethnicity or disability) and socially excluded groups (for example, people experiencing homelessness) (The King's Fund 2022). Those who experience persistent poverty are at particularly high risk of having poor physical or mental health (Marmot et al. 2020a). In the UK, one in five people live in poverty and do not have enough resources to meet their basic needs (The Health Foundation 2018). More recent attention has focused on rising food, energy and fuel prices post COVID-19 pandemic and the ongoing effects of the conflict in Ukraine (Harari et al. 2022). This is an ongoing concern as there is a cyclical relationship as “poverty damages health and poor health increases the risk of poverty” (The Health Foundation 2018, online).

In the analysis of the causes of health inequalities in England, Marmot et al. (2010) reported that in England between 1.3 and 2.5 million extra years of life would have otherwise been enjoyed by many people who are dying prematurely as a result of health inequalities. Health inequalities result from social inequalities, with those who are in a lower social position experiencing worse health. Ten years on what is clear from the evidence base is that these inequalities in health have widened, with a continued decline in life expectancy in the most deprived areas across all of the UK and especially for women (Marmot et al. 2020a). Furthermore, the COVID-19 pandemic has widened health inequalities across the UK for those already experiencing health inequalities, such as those in the most socially deprived areas, people from ethnic minority backgrounds or those having underlying health conditions (Marmot et al. 2020b). In February 2022, the UK Government published the “levelling up” White paper which outlines plans for reducing regional inequalities in a broad range of areas, which include health, by 2030 (HM Government 2022).

In 1971, Tudor-Hart published a seminal article where he described the “inverse care law” in which those individuals from socially disadvantaged backgrounds with the greatest health needs were tending to receive less adequate healthcare. Although dated, the inverse care law is still apparent within the NHS today (Fisher et al. 2022) as well as across health care systems worldwide (Cookson et al. 2021) and has implications for vulnerable populations within healthcare (Brown et al. 2022). What is

becoming apparent across the research literature is a growing awareness of vulnerable populations experiencing increasing healthcare inequalities (Copeland 2007; Grabovschi et al. 2013; Havrilla 2017; de Groot et al. 2019). What we know is that when people have limited access to healthcare, they may experience poor quality care and engage in more risky health related behaviours (such as smoking and excess alcohol use) and, consequently, they may experience worse health outcomes and health inequalities (The King's Fund 2022).

Several studies have reported differences in access to care, the availability of treatments, and the quality and experience of care, which become evident when comparing vulnerable to non-vulnerable groups (Nyamathi et al. 2007; Waisel 2013; AHRQ 2021). This has been amplified as a result of the COVID-19 pandemic (Germain and Young 2020; Jensen et al. 2021; Smolić et al. 2021). There is a growing body of work that explores healthcare inequalities for those living with chronic illness and disability (Ramjan et al. 2016; Iezzoni 2022) and PLWD (Cooper et al. 2016; Giebel et al. 2021). For PLWD a variety of socio-economic factors are cited as being the cause of unmet healthcare needs such as rurality, ethnicity, age, and socio-economic background (Cations et al. 2017; Pierse et al. 2020; Giebel et al. 2021). In developing a conceptual framework for understanding healthcare disparities experienced by individuals with disabilities, Meade et al. (2015) described how the interaction between personal factors (for example, race/ethnicity, gender, income) and factors within the healthcare system (termed environmental factors) can affect healthcare access and quality.⁹

A considerable amount of literature has been published on health inequalities for individuals living with SMI in relation to access to healthcare, treatment, experience, quality of care, support and health outcomes (PHE 2018; House of Commons Health and Social Care Committee 2021). Several lines of evidence suggest that such inequalities are often exacerbated when an individual with a SMI also has a long-term physical condition such as diabetes (NICE 2016) or chronic kidney disease

⁹ A review of the literature that was conducted alongside the development of the model found that individuals with disabilities experience higher rates of early death and preventable chronic conditions and are also more likely to have unmet healthcare needs, use fewer medical services associated with preventive care or health maintenance experience, have more severe medical complications and have more hospital admissions than those without disabilities (Meade et al. 2015).

(Cogley et al. 2022). The prevalence of multiple health conditions, multimorbidity, is increasing, and the care of an individual with multimorbidity is challenging (NIHR 2021). Data from several sources have indicated that challenges arise because the delivery of care is often based around the treatment of single conditions (Grabovschi et al. 2013, Boost 2018). In a review of physical illness and schizophrenia, Leucht et al. (2007) reported that the result is often unequal access to healthcare, but further research in this area is sparse.

In this critical commentary I explore healthcare inequalities for the vulnerable groups included within the published works¹⁰ as they navigate the healthcare system, either when accessing healthcare (**papers 1 and 2**), including admission and discharge (**papers 3 and 4**) or whilst experiencing care in the acute hospital setting (**papers 5 and 6**) while at the same time acknowledging the impact of social or structural disadvantages.

2.3. Theories of vulnerability

Explanations for why vulnerable groups experience poor health and health inequalities are important for guiding and directing healthcare (Havrilla 2017). A number of different models and theories of vulnerability have been reported across the literature and applied within healthcare settings. These include, for example, the Behavioural Model for Vulnerable Populations (Gelberg et al. 2000), the General Model of Vulnerability (Shi and Stevens 2005), the Theory of Self-Care Management for Vulnerable Populations (Dorsey and Murdaugh 2003) and the VPCM (Flaskerud and Winslow 1998). Although all the models define vulnerability slightly differently, they all agree that vulnerability is a concept which:

Constitutes a human condition in which the individual does not have the appropriate skills to deal with a great threat or harm
(Morante-García et al. 2022, p. 1294).

The dominant theory in the literature is the work of Flaskerud and Winslow (1998),

¹⁰ This includes adults with physical disabilities (**paper 1**), severe mental illness (**paper 2**), young people with complex mental health needs (**papers 3 and 4**) and frail older adults (**paper 5**) and people living with dementia (**paper 6**).

drawing on the framework of Aday (1993)¹¹ and others.¹² They developed a population-based framework known as the Vulnerable Populations Conceptual Model (VPCM). The VPCM describes the relationships between the concepts of resource availability, relative risk, and health status (Aday 1994; Flaskerud and Winslow 1998). Over recent decades, many healthcare researchers have explored vulnerability through the lens of the VPCM for a variety of vulnerable groups across a range of health conditions in both primary research and in reviews.¹³

A key component of the VPCM is resource availability which is regarded as the availability of socioeconomic and environmental resources. More specifically, socioeconomic resources have been characterised as the availability of human capital (income, jobs, education, and housing), social connectedness (integration into society and social networks), social status (prestige and power) and environmental resources (access to health care and quality of care).

There are many definitions and frameworks of healthcare access (Aday and Andersen 1974; Penchansky and Thomas 1981; Levesque et al. 2013). The seminal work of Aday and Andersen (1974, p.218) posited that it may be more meaningful to think about access “in terms of whether those who need care get into the system”. This approach, however, does not take into account other factors that can also influence entry or use of health services (Gulliford et al. 2002), and so simply thinking about access in terms of service availability is limited. This notion was developed further by Penchansky and Thomas (1981, p. 127) who suggested that access is about the “fit between the patient and the health care system”, encompassing the specific dimensions of availability, accessibility, accommodation, affordability, and acceptability. Another commonly cited framework is the conceptual framework of access to healthcare by Levesque et al. (2013) which was developed after undertaking a review of the literature on healthcare access. This framework offers a broader perspective to access which is defined as:

¹¹ Previously described on page 6.

¹² Link and Phelan 1996; Mann and Tarantola 1996; Mann 1998; Stanhope and Lancaster 1996.

¹³ Patients recovering from traumatic brain injury (Bay et al. 2006), children with asthma (Rodehorst et al. 2006), patients with chronic obstructive pulmonary disease (Dulemba et al. 2016) and vulnerable patients in primary care settings (Feryn et al 2022).

The opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use health care services and to actually have the need for services fulfilled.

(Levesque et al. 2013, p. 8)

A further component within the VCPM model is relative risk,¹⁴ which is regarded as exposure or susceptibility to risk factors. It is proposed that a lack of resources increases relative risk which in turn influences health status through delayed diagnosis, increased morbidity, and premature mortality. It is also proposed that poor health status in a vulnerable population may additionally deplete the availability of socioeconomic and environmental resources thus further exacerbating exposure to risk factors. These findings are compared to those groups who do receive such resources and are not exposed to these risk factors (Aday 1994; Flaskerud and Winslow 1998).

The final component within the VPCM is social connectedness or integration, which recognises that vulnerable groups of people who are marginalised,¹⁵ stigmatised (Link and Phelan 2001),¹⁶ or discriminated¹⁷ against are not socially connected or integrated and, as a result, may experience adverse health outcomes (Flaskerud and Winslow 1998).

The social model of disability (SMD) (Owens 2015) challenges discrimination and marginalisation for disabled people in society. Although as a model it has been questioned and criticised over the years (Shakespeare 2002; Shakespeare 2010; Owens 2015), it is still seen as having the potential to improve the lives of disabled people (Inclusion London 2022, online). The SMD was first proposed by the disability writer's campaigner – Mike Oliver (Oliver 1983) and had its origins in the 1970s through the work of the Disability Alliance and the Union of the Physically Impaired against Segregation (UPIAS1976). The SMD focuses on individuals and what they

¹⁴ “The ratio of the risk of poor health among groups exposed to risk factors versus those who are not so exposed” (Aday 1994, p. 487).

¹⁵ Marginalisation – “The process through which persons are peripheralized based on their identities, associations, experiences, and environment” (Hall et al. 1994 p. 25).

¹⁶ Stigma – “The co-occurrence of its components—labelling, stereotyping, separation, status loss, and discrimination—and further indicate that for stigmatization to occur, power must be exercised” (Link and Phelan 2001, p. 263).

¹⁷ Discrimination – “The unfair or prejudicial treatment of people and groups based on characteristics such as race, gender, age or sexual orientation” (APA 2019, online).

need, rather than their impairments, conditions, or illnesses (medical model). It remains of value as it recognises that inequalities can be caused by “barriers that society has put in place or chosen to ignore” (Hughes 2010, p. 511) and can include negative attitudes as well as a lack of access to services or support (Rohwerder 2015). Negative attitudes or implicit biases of HCPs based on prejudice, stereotype and stigma can result in discrimination and may prevent persons in certain vulnerable groups from having equal opportunities, especially in relation to the effectiveness and quality of the care provided (FitzGerald and Hurst 2017; Perry et al. 2018; Sossauer et al. 2019). Although the SMD has led to many positive outcomes for disabled people “they still experience many inequalities in their lives that contribute to their continuing exclusion“, such as in health and healthcare (Larkin 2009, p. 37).

People living with dementia (**paper 6**) and mental health issues – particularly those with SMI (**paper 2**) are often stigmatised. Stigmatising attitudes are prevalent in both HCPs and the general public (ADI 2019; Nyblade et al. 2019). Additionally, it is frequently reported that PLWD experience discrimination within healthcare settings (Knaak et al. 2017; ADI 2019). Such health condition-related stigma can undermine diagnosis, lead to reduced treatment options, and adversely influence the likelihood of positive health outcomes (Nyblade et al. 2019). Additionally, for people with mental illness, diagnostic overshadowing¹⁸ can lead to under diagnosing and poor treatment of their physical conditions (Hallyburton 2022).¹⁹ A diagnosis of dementia is associated with significant levels of stigma. This is of particular concern for women who additionally face what Bamford and Walker (2012, p. 123) coined a ‘triple jeopardy’ which can occur as a result of the intersection of age, gender and decline in cognitive functions.

To summarise, there are a number of challenges faced by particular vulnerable groups in relation to navigating the healthcare system. There are no single solutions for addressing these because of the interconnected nature of health inequalities,

¹⁸ Diagnostic overshadowing – “the misdiagnosis of one physical malady as being caused by a different, already diagnosed physical illness (Hallyburton 2022 p. 9).

¹⁹ I explore these issues further in chapter 3 for PLWD in relation to continence care in acute settings (**paper 6**) page 26 and those with SMI at end of life (**paper 2**) on page 17.

resource availability and health status²⁰. In applying the VPCM across the published works I have provided original and unique insights with the potential to inform further healthcare research practice and policy. This approach has been successfully applied by review authors identifying the opportunities and resources needed to achieve and maintain health in rural communities (Leight 2003), to re-integrate persons with brain injury to the community, to identify risk factors for those requiring nursing home placement (Palmer et al. 2014) or to review how inequalities in resource availability influence the health status of preterm infants (Weber et al. 2018). In this critical commentary I use the VPCM to demonstrate how the included published works make a logical, coherent, and original contribution to learning. In the next chapter, I outline the key themes that give the published works their defining coherence.

²⁰ Wicked problems.

Chapter 3. The context of the published works

This chapter presents the findings from each MMSR in the context of the existing literature on vulnerability and health inequalities presented above. A series of figures has been developed that explore the relationships between resource availability, relative risk and health status as part of the VPCM (Flaskerud and Winslow 1998) by placing the findings from each MMSR (text is highlighted in orange) in the context of the existing literature (text is highlighted in white). The original contribution to the knowledge base that each MMSR makes is identified directly under each figure.

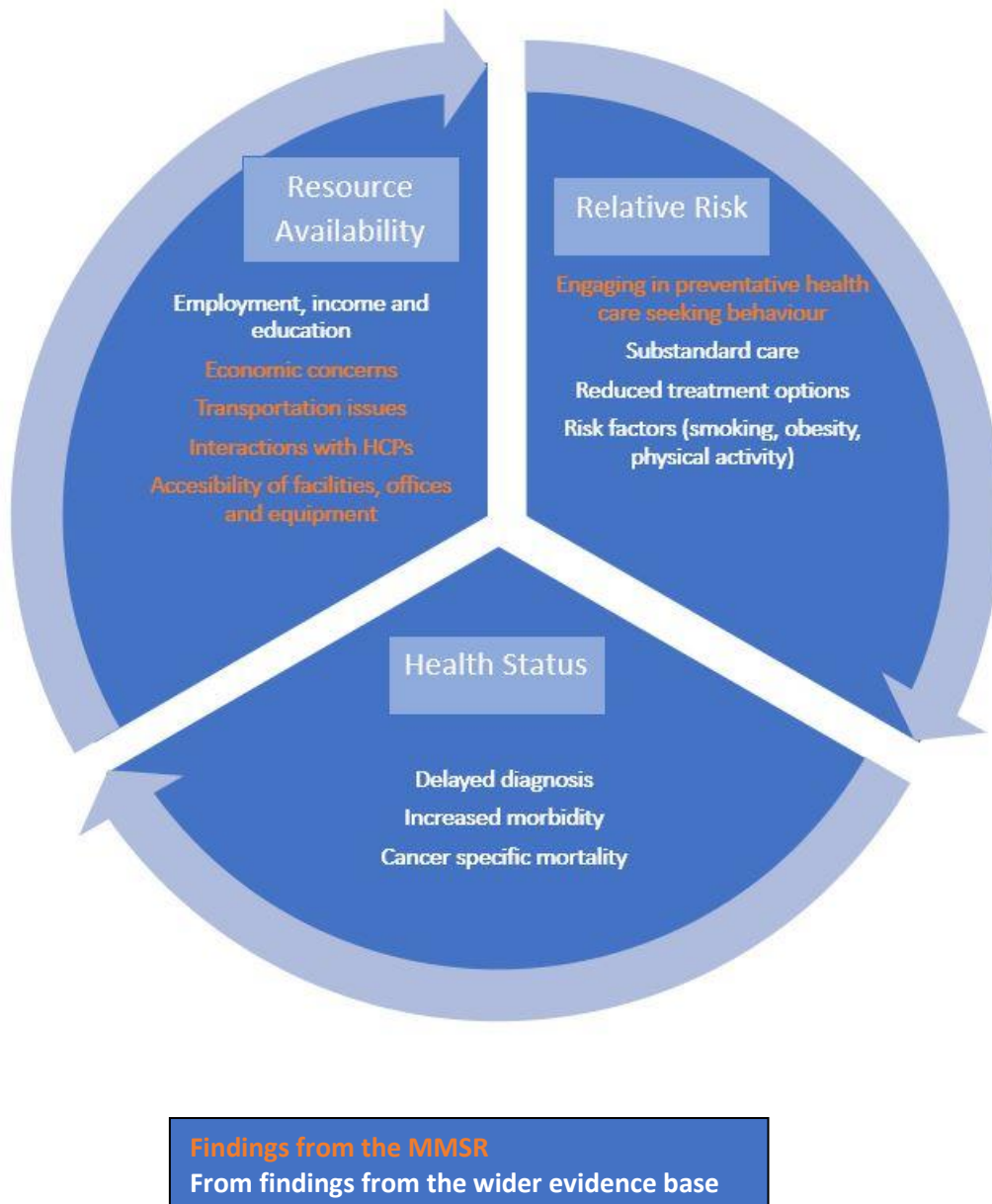
3.1. Paper 1

Aim: This MMSR investigated the barriers and facilitators of access to cancer services for people with physical disabilities and their experiences of cancer care.

Problem: Around one billion people (15%) of the world's population have a disability (WHO 2021c). There is evidence suggesting that people with disabilities have a higher prevalence of certain types of cancer which may be explained by the combination of an unequal balance in social determinants of health (employment, income, education) and an increased likelihood of risk factors associated with cancer (smoking, obesity, physical inactivity) (Ramjan et al. 2016; lezzoni 2022). Cancer services should be inclusive and accessible to everybody, including people with physical disabilities (Sakellariou et al. 2019). However, people with disabilities are less likely to attend for screening, are more likely to have their cancer detected and diagnosed at a later stage and tend to experience poorer access to cancer services compared to people without disabilities (Wisdom et al. 2010; Andresen et al. 2013; Peterson-Besse et al. 2014; Meade et al. 2015). Additionally, HCPs sometimes view people with disabilities as clinically complex and challenging when it comes to diagnosing and treating their cancer which may contribute to substandard care and reduced treatment options (Agaronnik et al. 2021; Reeves and Collingridge 2022). Due to these factors many people with disabilities could potentially experience worse health outcomes, specifically higher cancer mortality rates than those without disabilities (Andresen et al. 2013; Ramjan et al. 2016; Reeves and Collingridge 2022).

Application of the VPCM: In applying the VPCM to access to cancer services for adults with physical disabilities, I can identify the original contribution that the MMSR synthesis within **paper 1** has made to the knowledge base as (highlighted in orange in figure 1 and expanded upon below).

Figure 1: Vulnerable population conceptual model applied to access to cancer services for adults with physical disabilities



Key: HCP: healthcare professionals

Five themes consisting of 38 summary statements were identified²¹. The level of confidence in the summary statements derived from the qualitative and quantitative descriptive findings were assessed using the GRADE-CERQual approach²². There were 19 summary statements for which there were a high level of confidence, and these were used to inform the VPCM and in doing so illustrate the contribution to knowledge.

Under the construct of resource availability, four areas are important and include

- Accessibility of facilities, offices, and equipment (finding a suitable healthcare provider, physical access and parking issues, accommodating needs through adaptive equipment, assistance, physical positioning, physical pain and discomfort).
- Economic concerns.
- Transportation issues.
- Interactions with HCPs (attitudes and behaviours, knowledge and communication, gatekeeping).

Additionally, relative risk is operationalised as reasons for not engaging in preventative health care seeking behaviours and encompasses knowledge, beliefs, time constraints and priorities.

3.2. Paper 2

Aim: This MMSR identified and synthesized the evidence relating to the organisation, provision and receipt of care for people with SMI who have an additional diagnosis of advanced, incurable, cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months.

Problem: Dying well, regardless of a person's background, circumstance or location is considered a "fundamental aspect[s] of human dignity" (NHS England 2022, online) and access to palliative care and end-of-life (EOL) care is increasingly recognised as a human right (World Health Organisation 2020). There is evidence however, that people from certain groups, including those who are vulnerable, may experience inequalities in access as well as variability in the quality of care (CQC 2016;

²¹ Further detail provided within supplementary online material [four](#) for **paper 1**.

²² For explanation of GRADE-CERQual see page 38.

Hospice UK 2021; Tobin et al. 2022). These groups include people who are from different ethnic backgrounds or from gypsy and traveller communities, experience homelessness, reside in secure and detained settings, identify as LGBT²³, live in poverty, deprivation, and with lower socioeconomic status, have a non-malignant condition, and those who are socially isolated or live alone, located in remote or rural areas, or over the age of 85 (CQC 2016; Marie Curie 2016; Hospice UK 2021; PHE 2022). International evidence from systematic reviews (SRs) consistently describe differences in outcomes by ethnicity or socioeconomic status, with examples including not receiving specialist palliative care, getting acute hospital-based care (rather than specialist care) in the last three months of life, dying in hospital rather than at home or a hospice, as well as disparate access based on age, gender and geographical location (Dixon et al. 2015; French et al. 2021; Nelson et al. 2021; Tobin et al. 2022). There has been little written however, about people living with a pre-existing SMI who additionally develop advanced or life-limiting illnesses (such as incurable cancer and/or end-stage organ disease).

Application of the VPCM: In applying the VPCM to EOL care for adults with SMI, I can identify the original contribution that the MMSR synthesis within **paper 2** has made to the knowledge base as (highlighted in orange in figure 1 and expanded upon below).

²³ LGBT: lesbian, gay, bisexual and transgender

Figure 2: Vulnerable populations conceptual model applied to end-of-life care for adults with severe mental illness



Four themes consisting of 148 summary statements were identified²⁴. The level of confidence in the summary statements derived from the qualitative and quantitative descriptive findings (n=52) were assessed using the GRADE CERQual approach²⁵ and there were 10 summary statements with a high level of confidence. The quality

²⁴ Further detail provided within supplementary online material [four](#) and [five](#) for **paper 2**.

²⁵ For explanation of GRADE-CERQual see page 38.

of the summary statements (n=96) that were derived from the observational studies were assessed using the GRADE approach²⁶ and all were rated as very low quality. The summary statements with a high level of confidence (GRADE-CERQual) and the very low quality statements (GRADE) were used to inform the VPCM and in doing so illustrate the original contribution to knowledge.

Under the construct of resource availability, two areas are important and include:

- Partnership (ongoing interprofessional communication).
- Relationships between HCPs and people with SMI (connecting relationships, talking about death and dying, attitudes and beliefs of HCPs).

For the concept of relative risk, two areas are considered which are:

- Meeting individual and family needs (spiritual and psychosocial support, advocacy, EOL care preferences).
- Healthcare services and treatment utilisation in the last year of life²⁷.

Additionally, health status is operationalised as:

- No right place to die²⁸ (for example, dying at home, dying in a psychiatric hospital).
- Late diagnosis of life limiting disease (the impact of late diagnosis).

3.3. Papers 3 and 4

Aim: This MMSR explored what is known about the identification, assessment, and management of risk (where 'risk' is broadly conceived) in young people (aged 11–18) with complex mental health needs entering, using, and exiting inpatient child and adolescent mental health services in the UK.

Problem: In 2021, one in six children aged 5-19 in England had a probable mental disorder (approximately 1.3 million people) (Peytrignet et al. 2022) and since the COVID-19 pandemic the number of children and young people (CYP) experiencing mental health problems across the UK is growing (Grimm et al. 2022). Worldwide,

²⁶ For explanation of GRADE see page 38.

²⁷ Further detail provided within supplementary online material [five](#) for **paper 2**.

²⁸ Further detail provided within supplementary online material [five](#) for **paper 2**.

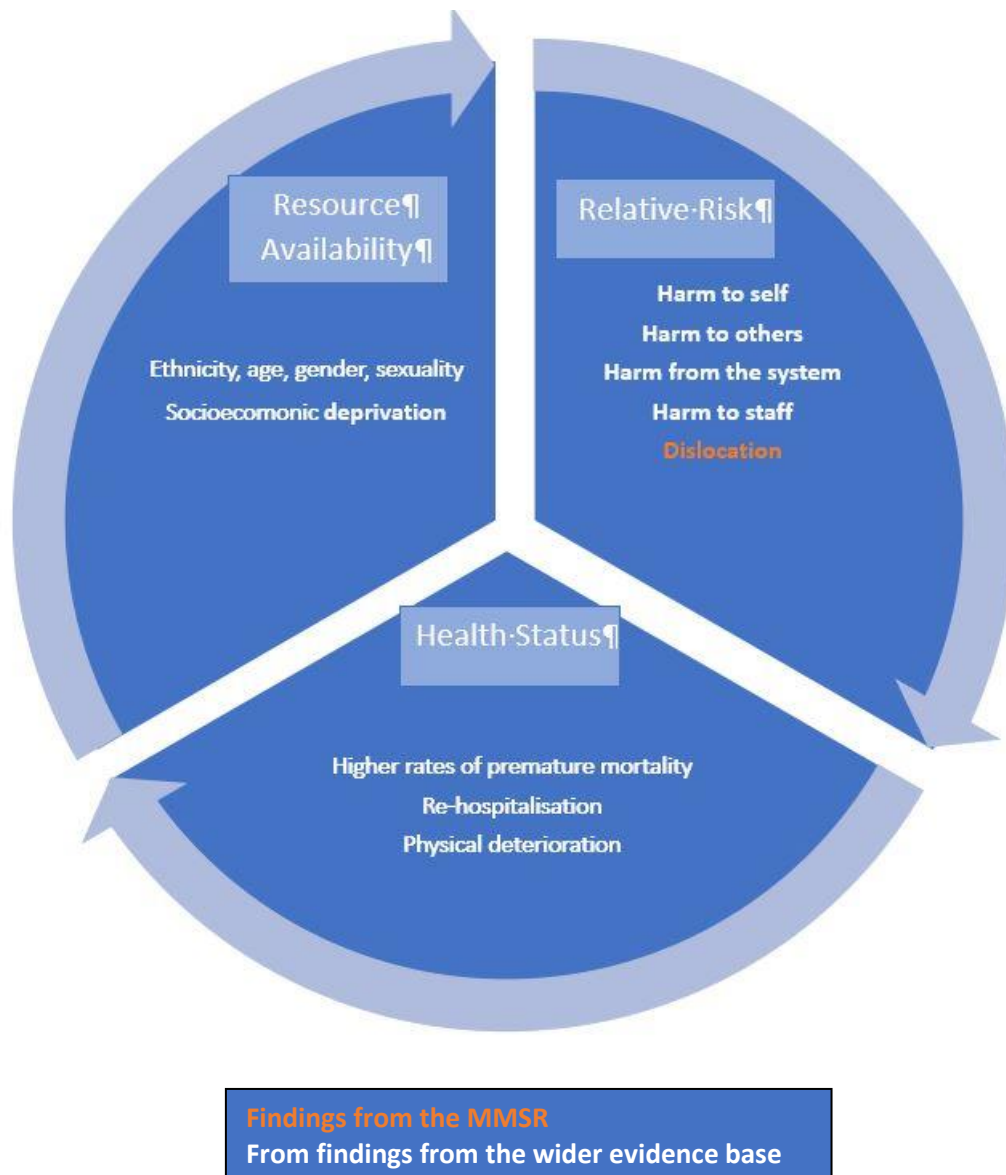
data from 2020 indicates that one seventh (14%) of 10-19-year-olds experience mental health conditions (WHO 2021a).

It is clearly documented across research and national prevalence data that there are disparities in the prevalence of mental health disorders by gender, sexuality, age, ethnicity, socioeconomic deprivation (Reiss 2013; Grimm et al. 2022; UK Parliament 2022) which have become even more apparent since the COVID-19 pandemic. (CQC 2022). These same disparities are evident with regard to the availability and accessibility of specialist mental health services (Grimm et al. 2022; UK Parliament 2022).

Most CYP who experience mental ill-health are cared for in the community with only those with the greatest levels of need requiring care and treatment in hospital. The risk of premature mortality in CYP accessing mental healthcare is elevated relative to the general population, reflective of an increase in the rates of death from suicide (McHugh et al. 2022). Although suicide rates vary globally the WHO (2021a) report that suicide is the fourth cause of death for 15-19 year olds. Admitting a suicidal CYP to an inpatient unit is a common response to mitigating such risks. Although hospital care provide sanctuary, it can however bring additional unintended risks (Hannigan et al. 2015). Subotsky (2003) presented a typology of risk for child and adolescent mental health services which includes harm to self, harm to others, harm from the system and harm to staff. However, in investigating the risks for young people moving into, journeying through, and out of inpatient mental health care I demonstrated (**paper 3 and 4**) that there are a series of additional risks which are important to people with stakes in the child and adolescent mental health system. These were risks associated to young people's psychological and social development, their educational achievement, and family and peer relations.

Application of the VPCM: In applying the VPCM to inpatient care for young people with complex mental health needs I can identify the original contribution that the MMSR synthesis within **paper 3 and 4** has made to the knowledge base as (highlighted in orange in figure 1 and expanded upon below).

Figure 3 Vulnerable populations conceptual model applied to inpatient care for young people with complex mental health needs



Two themes consisting of 28 summary statements were identified²⁹ and the level of confidence was assessed using the GRADE-CERQual approach³⁰. There were 11 summary statements for which there was a high level of confidence based on GRADE-CERQual. The quality of the summary statements (n=2) that were derived from the observational studies were assessed using the GRADE approach³¹ and all were rated as low quality. The summary statements with a high level of confidence

²⁹ See [appendix 4](#) for CERQual and GRADE summary of findings for **paper 4**

³⁰ For explanation of GRADE-CERQual see page 38.

³¹ For explanation of GRADE see page 38.

(GRADE-CERQual) and the low quality statements (GRADE) were used to inform the construct of relative risk within the VPCM and in doing so illustrate the original contribution to knowledge.

Relative risk was conceptualised around one theme which was 'dislocation'. The term 'dislocation' was used to refer to the risks of being removed from normal life; risks to friendships; risks to families and risks to education³².

3.4. Paper 5

Aim: This MMSR investigated assistance at mealtimes for patients (over 65 years) in hospital settings and rehabilitation units and asked what goes on, what works and what do patients, families and HCPs think about it?

Problem: In the UK, around one in ten people 65 years and older (approximately one million people) are estimated to be malnourished or are at risk of malnutrition (AgeUK 2021). Within hospital settings, on admission, it is estimated that between 30-50% of older people are already malnourished or at risk of malnutrition (Avelino-Silva and Jaluul 2017; Stratton et al. 2018; Leij-Halfwerk et al. 2019; MTF 2022). Some older people are also at risk of developing malnutrition during their hospital stay (Barker et al. 2011; Avelino-Silva and Jaluul 2017). If oral nutritional intake is below 50% of requirements for more than three days or if risk factors are present that may either reduce dietary intake or increase requirements, then the older person can be at risk of malnutrition (Volkert et al. 2019). The main risk factors in acute care settings include the disease status or condition; eating, appetite or digestion issues; medication-related; and altered cognition/psychology (MTF 2021; Yaxley et al. 2021). There are also a variety of social factors that impact on malnutrition that frequently intersect with health conditions for older people within the community. A strong relationship exists between the levels of poverty and malnutrition in older people as low income can affect a person's ability to purchase sufficiently nutritious food (MTF 2021). Malnutrition is associated with poorer clinical outcomes (e.g., increased infections, wounds, and complications), prolonged length of stay, hospital re-admissions, higher rates of mortality (Avelino-Silva and Jaluul 2017; Stratton et

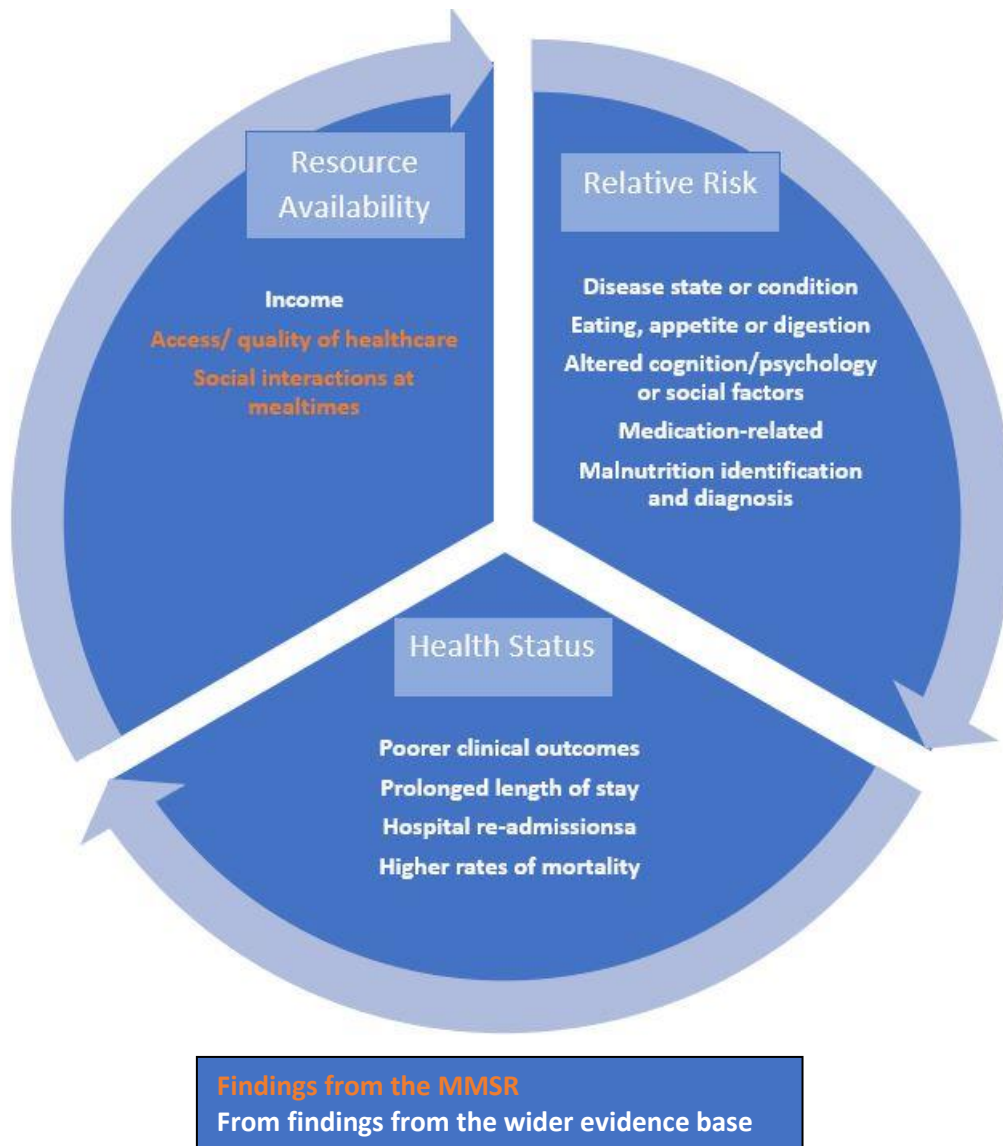
³² For further details see [appendix 4](#)

al. 2018; Uhl et al. 2021) and increased hospital costs (Khalatbari-Soltani and Marques-Vidal 2015).

It is, therefore, important that those who need assistance at mealtimes are identified and given the support that they need alongside screening for pre-existing malnutrition (MTF 2022). The beneficial effects of supportive interventions such as mealtime assistance have been highlighted across international guidelines (Committee of Ministers 2003; Volkert et al. 2019) and SRs for adults over 18 years (Green et al. 2011; Whitelock and Aromataris 2011) as having the potential to enhance nutritional intake, improve clinical outcomes and patient experience.

Application of the VPCM: In applying the VPCM to mealtime assistance for older adults in hospital settings, I can identify the original contribution that the MMSR synthesis within **paper 5** has made to the knowledge base as (highlighted in orange in figure 1 and expanded upon below).

Figure 4: Vulnerable populations conceptual model applied to mealtime assistance for older adults in hospital settings



The synthesis identified a number of initiatives which can be used to support older patients at mealtimes in hospital settings and rehabilitation units. The findings that led to ‘strong’ recommendations³³ were used to inform the construct of resource availability within the VPCM and in doing so illustrate the contribution to knowledge.

³³ Grade A – “A ‘strong’ recommendation for a certain health management strategy (1) it is clear that desirable effects outweigh undesirable effects of the strategy; (2) where there is evidence of adequate quality supporting its use; (3) there is a benefit or no impact on resource use, and (4) values, preferences and the patient experience have been taken into account’ (JBI 2014, p. 1)

Two areas were identified and include *access / quality of healthcare and social interaction at mealtimes*³⁴.

3.5. Paper 6

Aim: This MMSR identified successful strategies across all care settings that could then be used to inform innovations in continence care for PLWD in the acute hospital setting.

Problem: There are currently around 994,000 PLWD in the UK (Alzheimer's Research UK 2022a), and around 55 million people across the world (WHO 2021b). This number is likely to rise by 1.6 million by 2050 (Alzheimer's Research UK 2022b). In the UK, at any given time, one in four hospital beds will be occupied by PLWD (RCP 2019) and they will have higher admission rates compared to people without dementia (Shepherd et al. 2019).

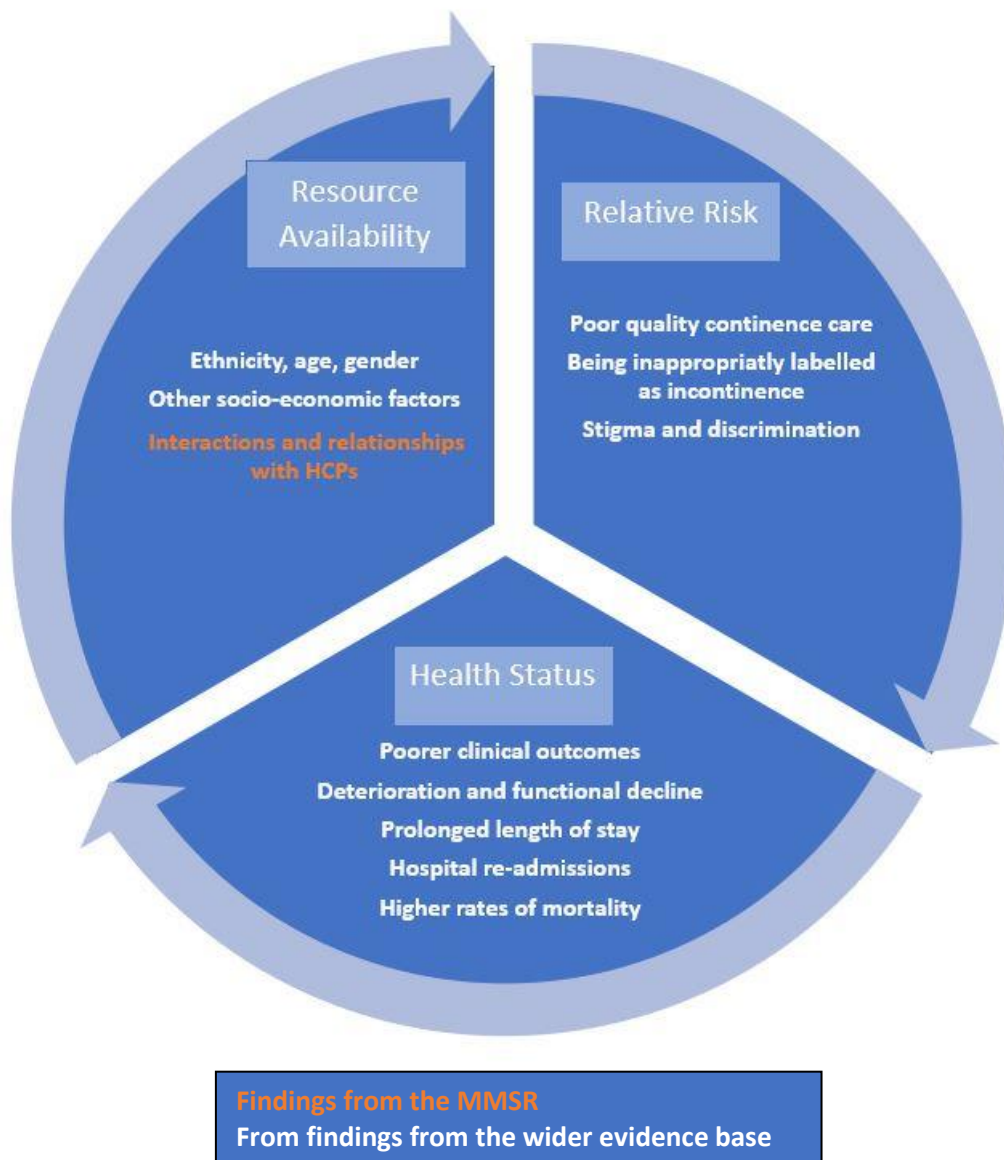
National audits conducted during acute admissions consistently identify PLWD and patients (> 65 years) as being at high risk of being inappropriately labelled as incontinent and of receiving particularly poor continence care during acute admissions (Potter et al. 2007; Wagg et al. 2010; Harari et al. 2014). Incontinence is associated with an increased risk for falls that could lead to fractures (Moon et al. 2021). Additionally, poor quality continence care, such as the inappropriate use of disposable continence pads and catheters, have been consistently reported as key management issues of continence for hospitalised older adults (Colborne and Dahlke 2017; Featherstone et al. 2022). A common complication of in-dwelling catheters is urinary tract infections (Hollenbeak and Schilling 2018) and their overuse can lead to higher rates of such infections in healthcare settings (Kranz et al. 2020). Additionally, Percival et al. (2001) suggests that the overuse of pads can create dependency and risks patient infection as well as affecting patient hygiene, skin integrity (such as pressure ulcers) and dignity.

For the PLWD the consequences of hospitalisation alongside issues linked with incontinence described above can be associated with an increased risk of deterioration and functional decline along with longer hospital stays, unscheduled re-

³⁴ Reported within [table 5](#) of the published work for **paper 5**.

admissions, premature institutionalisation, increased mortality (Mukadam and Sampson 2011; Lehmann et al. 2018; Shepherd et al. 2019; Gyesei-Appiah et al. 2020) and increased healthcare costs (Hollenbeak and Schilling 2018).

Figure 5: Vulnerable populations conceptual model applied to continence care in acute settings for people living with dementia



Key: HCPs: Healthcare professionals

Application of the VPCM: In applying the VPCM for continence care in acute settings for PLWD, I can identify the original contribution that the MMSR synthesis within **paper 6** has made to the knowledge base (highlighted in orange in figure 1 and expanded upon below).

Three themes consisting of 30 summary statements³⁵ were identified. The level of confidence in the summary statements derived from the qualitative and quantitative descriptive findings (n=26) were assessed using the GRADE-CERQual approach³⁶. There were six summary statements with a moderate level of confidence and one with a high level of confidence and these were all used to inform the construct of resource availability within the VPCM and in doing so illustrate the original contribution to knowledge.

Resource availability was conceptualised around one theme which was “communication that is dignified, person-centred, and respectful”. Specifically, this referred to interactions and relationships with HCPs which encompassed communicating in a dignified way, attitudes, importance of non-verbal cues and strategies for improving communication.

³⁵ Further detail provided within [appendix 5](#) for **paper 6**.

³⁶ For explanation of GRADE-CERQual see page 38.

Chapter 4. Justification for choice of research methodology

This chapter presents a justification for the choice of research methodology. The published works contributing to this critical commentary are all MMSRs which are a review type in the wider family of evidence synthesis (Aromataris et al. 2022). Evidence synthesis denotes any method of identifying, selecting, and combining results across a range of sources in the context of what is already known to come to an overall understanding of a topic. Mixed methods systematic reviews take their place along with other evidence synthesis methodologies, such as effectiveness, experimental qualitative reviews, scoping, and umbrella reviews amongst many others (Munn et al. 2018; Aromataris et al. 2022).

A number of international interdisciplinary groups of academics have emerged that promote evidence syntheses and offer training in the specialised skills required to conduct them.³⁷ All these groups have developed methods and guidance to bring research evidence together. The evidence syntheses within this critical commentary draw upon methodology from both the JBI and the EPPI-Centre (see [appendix 3](#)).

In the next section I provide a detailed understanding of the specific techniques and methods used within evidence synthesis and MMSRs as well as providing an evaluation and critique of the field.

4.1. Evidence syntheses within healthcare

The large volume of research evidence on any one particular topic from across numerous individual studies has grown over the past decade (Poklepović and Tanveer 2019; Aromataris and Munn 2020; Lasserson et al. 2021). There is international consensus from groups that develop and use evidence syntheses regarding the need to be cautious about placing too much confidence in the results of single studies to resolve clinical questions, as they are not always able to provide definitive answers (Gough et al. 2020). This view is supported by the seminal work of Pettricrew and Roberts (2006, p.5) who noted that when contradictory evidence is presented, it is important to know which studies to believe and to be able to determine where the “balance of truth lies”. The problem is such a complexity of

³⁷ Such entities include the JBI Collaboration, the Cochrane Collaboration, the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) amongst others

evidence may result in less clear conclusions even if the same topic is covered, making it difficult for HCPs and decision makers to make informed and appropriate decisions (Aromataris and Munn 2020; Lasserson et al. 2021).

The difference between standard literature reviews and the different types of reviews within the evidence synthesis toolkit lies in the methods used to conduct the review. An evidence synthesis seeks to find all the empirical evidence that is available and relevant based on pre specified eligibility criteria to address a specific research question (Lasserson et al. 2021). This is achieved by using explicit and systematic methods for selecting, appraising, and synthesising primary research studies with a view to minimising bias: methods that are rigorous and transparent (Aromataris and Munn 2020). The main weakness of literature reviews is that they do not all apply the same levels of rigour, and as a result, bias can be introduced in choosing which studies to include and two reviews on the same topic could be written with completely opposite conclusions (Pettricrew and Roberts 2006). Another potential weakness is that even if a literature review is conducted by an expert in the field, there is a danger that they could inadvertently or deliberately tailor the review to confirm their own viewpoints on a topic. Good quality literature reviews play a part in exploring healthcare topics (Baethge et al. 2019) and they are considered by some to be a “potentially complementary form of scholarship” (Greenhalgh et al. 2018, p. 4). Greenhalgh et al. (2018) argues that evidence syntheses seek to answer narrowly focussed questions whereas narrative reviews can provide a deep understanding through interpretation and critique of broader topic areas in the form of a scholarly summary.

4.2. The value of mixed methods systematic reviews

In 2005, Dixon-Woods and colleagues highlighted limitations of evidence syntheses that rely on quantitative evidence (effectiveness reviews) alone and noted that decision makers were calling for “more inclusive forms of evidence”.

Qualitative evidence synthesis is recognised as a method that “goes beyond what works” approach in an effectiveness review enabling the development of a richer understanding of the topics being explored (Flemming and Noyes 2021, p. 1). Over recent years there have been significant developments in incorporating both

quantitative, qualitative and mixed methods studies in the form of MMSRs evidence in contributing to a broader understanding of a topic based on the best available evidence (Harden et al. 2018; Stern et al. 2020). A seminal exploration of MMSRs by Heyvaert et al. (2013, p. 671) stated that MMSRs are a way of providing “more complete, concrete, and nuanced answers”.

Evidence synthesis methodologists recognise that MMSRs can present their own unique set of challenges mainly due to the different synthesis options that are available (Ferguson et al. 2020; Hong et al. 2020). This can be attributed to the complexity of combining data that “are similar but not identical” (Ferguson et al. 2020, p. 590). Sandelowski et al. (2000) presented some seminal work on research designs that could be used to conduct MMSRs but acknowledged that as a method, further exploration was needed. Now over 20 years later there is still considerable debate surrounding the methodology that should be used for the integration in MMSRs and guidance is still embryonic and mainly theoretical in nature (Harden et al. 2018; Stern et al. 2020).

Hong et al. (2017) examined the methods used across 459 MMSRs and although they identified a lack of consistency in terminology, two main frameworks for synthesising data across qualitative and quantitative studies were identified. This review, and further work by the same authors (Hong et al. 2020), showed that of these two approaches the one that predominates the literature is the convergent approach, in which synthesis occurs simultaneously and qualitative and quantitative methods are complementary as opposed to the sequential approach in which synthesis occurs consecutively (Hong et al. 2017). The most recent MMSR guidance developed by the JBI (Stern et al. 2020) presents convergent integrated³⁸ and convergent segregated approaches³⁹ which is informed by the typology developed by Hong et al. (2017) and seminal work undertaken by Sandelowski et al. (2000, 2006, 2013).

³⁸ Convergent integrated – “Which involves data transformation and allows reviewers to combine quantitative and qualitative data” (Stern et al. 2020, p. 4).

³⁹ Convergent segregated – “Which involves independent synthesis of quantitative and qualitative data leading to the generation of quantitative and qualitative evidence, which are then integrated together” (Stern et al. 2020, p. 4).

4.3. Contribution to knowledge development

The individual publications presented in this critical commentary all made a substantial, original contribution to knowledge as illustrated in figure 6. Within evidence syntheses, new knowledge is generated when the data from primary studies are transformed and assembled in order to address the research question (Thomas et al. 2017). Evidence synthesis is more than the sum of individual parts, forming a new and different understanding of the area being explored. It is this summary of new knowledge of various types that has the potential to inform policy and clinical decision making, see section 4.4 (pages 34 to 39). Therefore, in this context I argue that evidence syntheses are a type of research methodology that can form the basis of a research thesis (Puljak and Sapunar 2017).

A further reflection as to why evidence syntheses are suitable for the foundation of a thesis is their originality. There is debate in the field however, with some methodologists arguing all evidence syntheses are original research as they synthesise primary research (Meerpohl et al. 2012; Aveyard and Sharp 2017). In contrast, a mixed methods study (Krnjic Martinic et al. 2019) that investigated the attitudes of editors of core clinical journals in this area reported that some journal editors do not consider all evidence syntheses as original research.⁴⁰ Other considerations that have been reported across the literature are that SRs should add value and should be novel and useful with the issue of originality being inconsequential (Biondi-Zoccai et al. 2011; Krnjic Martinic et al. 2019).

⁴⁰ Some only considered systematic review with meta-analysis as an original study, while others recognised that meta-analyses are not always justified because of the heterogeneity of the included studies. Some journal editors proposed that the originality of a SR would depend on the final synthesis, whereas others felt evidence syntheses are not original research as they depend on data collected by others although there are a range of study designs where data are not collected from primary sources, for example retrospective cohort studies (Krnjic-Martinic et al. 2019).

Figure 6: Examples of new knowledge from published works

Vulnerable group : Adults with a physical disability (Paper 1)

New knowledge: Barriers to engaging with preventative health care which included arranging assistance and transportation, the actual process of being given assistance, including attendant services being difficult to organise, a lack of continuity in carers, inappropriate transfers and undesirable levels of physical handling, and concerns for women regarding privacy when undergoing mammograms.

Vulnerable group : Adults with severe mental illness (Paper 2)

New knowledge: The structure of mental health and EOL care systems means that people with severe mental illness at the end-of-life often have difficulty getting the services they need, whilst the education and practice of professionals in each of these two systems can create barriers to the provision of care.

Vulnerable group : Young people with complex mental health needs (Papers 3 & 4)

New knowledge: The less obvious risks of 'dislocation' which was operationalised as risk of being removed from normal life, of experiencing challenges to identity, of being stigmatised and to the risks to friendships and families, and to education.

Also 'contagion' which was operationalised as the risks of learning unhelpful

Vulnerable group : Older adults (>65 years) (Paper 5)

Healthcare system : Acute hospital setting

New knowledge: Any initiative that involves supporting the older patients (>65 years) with setting up the tray, having meals within reach, assistance with opening packaging is beneficial.

If nurses are to fulfil the role of mealtime assistance, then mealtimes should be viewed as a high priority and all healthcare staff should limit other activities to allow patients to eat uninterrupted, providing support where required.

Vulnerable group : Adults with dementia (Paper 6)

Healthcare system : Acute hospital setting

New knowledge: People living with dementia are not always able to recognise that they have continence needs, need to go to the toilet, or verbally communicate that they need assistance.

Continence care is often considered a low priority by some healthcare staff.

4.4. Potential impact

This section explores the potential impact of evidence syntheses in general as well as the impact of published works in terms of knowledge production, research targeting, informing policy development and as having a direct impact on practices/services (Bunn et al. 2014; Gough et al. 2020).

The scientific impact of a published work in terms of the research community can be measured quantitatively using bibliometrics (Agarwal et al. 2016; Tahamtan and Bornmann 2019) and more specifically citation counts⁴¹. It is acknowledged that the citation score does not reflect the quality of the articles published or whether the citation is portrayed in a negative or positive context (Agarwal et al. 2016). The responsible use of metrics forms part of the San Francisco Declaration on Research Assessment (DORA)⁴² and it is advised that researchers use a range of article metrics and indicators as evidence of the impact of individual published articles. The citation scores from the published works included within this critical commentary are displayed in table 1.

Table 1: Citation scores of included publications as of 26th June 2022

Published work	Citation scores		Textbooks identified on google scholar
	Scopus	Dimensions	
Adults with a physical disability - Paper 1	16	19	One textbook (Lollar et al. 2020)
Adults with severe mental illness - Paper 2	2*	2*	
Young people with complex mental health needs - Paper 3 - Paper 4	13 6	14 4	One textbook (Mason et al. 2021)
Older adults (>65 years) - Paper 5	22	18	Six textbooks (Miller 2018; Yoost and Crawford 2019; Murry et al. 2020; McSherry et al. 2021; Makic and Martinez-Kratz 2022; Wilkins 2022).
Adults with dementia - Paper 6	1**	1**	

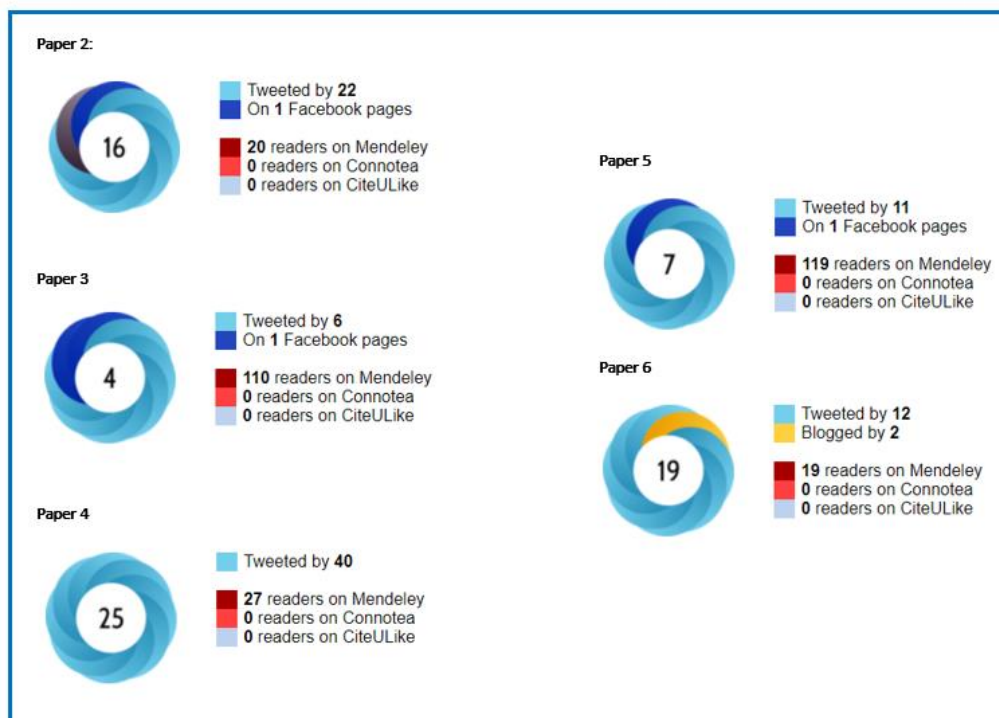
*Published in September 2021; ** Published in July 2021

⁴¹ Citation count – defined as “the number of citations a publication has received and measures citations for either individual publications or sets of publications” (Agarwal et al. 2016, p.297).

⁴² <https://sfdora.org/read/>

In recent years the inclusion of different data sources and the collection of content from a wide range of social network services has complemented the world of conventional metrics as is referred to as article-level metrics (ALM) (Melero 2015). The ALM⁴³ of the included publications are displayed in figure 7. It can be assumed that the frequency with which a work is cited reflects its influence and importance and the use of ALM can give an indication that the publications have been read and discussed (Bunn et al. 2014) as demonstrated across **papers 1, 3-5**.

Figure 7: Article level metrics for included publications as of 26th June 2022



However, a key message on research impact from the Leiden Manifesto for Research Metrics⁴⁴ is that reading and judging a researcher's work is more appropriate than depending on one number and that a qualitative judgement of a researcher's portfolio should also be considered (Hicks et al. 2015).

The influence of evidence syntheses including MMSRs in identifying gaps in knowledge and methodological concerns with the evidence base, which can then be used to inform and improve future work in the topic area, is widely reported

⁴³ There is currently no ALM for **paper 1** and the most recently published MMSRs (papers 2 and 6) have not yet had the opportunity to be cited widely as it is estimated that citation volume generally peaks between three and four years post publication.

⁴⁴ <http://www.leidenmanifesto.org/>

(Poklepović and Tanveer 2019; Gough et al. 2020; Stern et al. 2020). This is described by Bunn et al. (2014) as research targeting which additionally has the potential to lead directly to follow-on research (Bunn et al. 2014). Figure 8 illustrates the evidence gaps for the SRs presented within this critical commentary.

Figure 8: Evidence gaps from published works included in this critical commentary

Paper 1	<ul style="list-style-type: none"> • Qualitative studies that explore the experiences of cancer treatment and accessing preventative health care services for men with disabilities
Paper 2	<ul style="list-style-type: none"> • Qualitative studies that explore the experiences of people and their carers with severe mental illness at the end-of-life
Papers 3/4	<ul style="list-style-type: none"> • High quality quantitative studies that focus on identifying, assessing and managing the less obvious risks of dislocation and contagion within in-patient settings
Paper 5	<ul style="list-style-type: none"> • Quantitative studies looking at encouraging relatives/visitors to visit at mealtimes and to offer support to patients
Paper 6	<ul style="list-style-type: none"> • Quantitative studies that focus on continence care and communication for people living with dementia

Two follow-on research studies have arisen so far. Firstly, the evidence synthesis (**paper 1**) was part of a wider body of work titled Challenges of Cancer and Disability Study (CoCaDS),⁴⁵ and this led to a full-time PhD funded through the Knowledge Economy Skills Studentship (KESS) in collaboration with Tenovus. The aim of this funded project was to investigate disparities in cancer care for people with physical disabilities in Wales. Secondly, the evidence synthesis (**paper 2**) led to a full-time PhD funded through KESS2 which explored young people's social connections during periods of inpatient mental healthcare and the processes associated with the

⁴⁵ Funded by Tenovus Cancer Care (IGrant number TIG2017-05).

“less obvious risks” to children and young people in inpatient mental health services. These “less obvious risks” were identified in the evidence synthesis.

The evidence synthesis (**paper 6**) was conducted as part of a wider ethnographic study⁴⁶ and was produced prior to data collection. The findings were used to refine the approach to fieldwork and analysis, and to inform the development and feasibility of interventions. Specifically, providing the researchers with a focus for initiating the process of early thinking and theorising during data collection and analysis and highlighting key areas of communication, language, and the importance of non-verbal cues. These key areas were used to stimulate questions during the ongoing iterative analytic process.

A further area of impact for systematic review findings including those from MMSRs is that they have the potential to inform policy development (Gough et al. 2020; Stern et al. 2020). This can include policies agreed at national or local levels in the form of clinical or local guidelines and policies developed by those responsible for training and education (Bunn et al. 2014). I show that **paper 5** contributed directly to the Health Services Executive (Ireland), Food, Nutrition and Hydration Policy⁴⁷. For **paper 6**, the NIHR centre for dissemination has undertaken a themed review⁴⁸ of NIHR evidence on continence care for PLWD of which the evidence synthesis (**paper 6**) and wider ethnographic study will make a valued contribution. The wider research team has also worked with key dementia care, clinical, and policy networks.⁴⁹

⁴⁶ National Institute of Health & Social Care Research (NIHR) funded project 15/136/67 that focused on the routine work of continence care for PLWD admitted to acute hospital settings within the wider context of the everyday care carried out by nurses and healthcare assistants.

⁴⁷ Health Services Executive (Ireland), Food, Nutrition and Hydration Policy for adult patients in acute hospitals published in November 2018. Specifically contributing to the evidence statement / summary (Section 8.1 p. 81) and in informing key recommendations for making mealtimes matter (Section 8.2, p. 82).

⁴⁸ <https://evidence.nihr.ac.uk/themedreview/continence-dementia-and-care-that-preserves-dignity/>

⁴⁹ This has provided new knowledge that has informed and contributed to the development of the Dementia-Friendly Hospital Charter (supported by Welsh Assembly Government) and the All Wales Inpatient Falls Network (the goal is to develop awareness of the role of risk management and policies in ward cultures of continence care for PLWD).

In the recent JBI guidance, Stern et al. (2020) concluded that MMSRs are an important development in the field of evidence-based healthcare as they extend the capacity of the review findings to assist in clinical decision making which in turn can have an impact in practices/services. However, Bunn et al. (2014, p. 12) points out that it is not always possible to tell whether a systematic review has changed the behaviour of HCPs or directly impacted clinical practice and services. New knowledge, however, supplements the existing body of knowledge and it is often the cumulative effects of such evidence that has the potential to directly impact clinical practice and advances in healthcare. Many research projects may lie behind a specific advance in healthcare (Bunn et al. 2014). This concurs with the recent work of Gough et al. (2020, p.3) who suggested that evidence syntheses in systematically identifying and assessing all the available evidence for a research questions seeks to prevent decision makers from “cherry picking” findings of single or small scale studies.

A variety of structured approaches are available to the reviewer that can facilitate progressing from evidence to decision making such as GRADE⁵⁰, GRADE CERQual⁵¹ or JBI ConQual⁵². The goal across all these approaches is to help decision makers decide how much importance to place on individual review findings. At present all of these approaches are applied to method-specific findings and currently there is no recommended approach for assessing confidence for MMSR findings (Noyes et al. 2019). Over the last eight years however, I have made a unique contribution⁵³ to the field in unofficially adapting⁵³ GRADE-CERQual for use in MMSRs (**papers 1, 2, 3 and 6**) to synthesise data from descriptive surveys and other non-intervention quantitative studies for the assessment of the confidence of synthesised findings alongside the qualitative studies. The adaptation was performed

⁵⁰ GRADE (Grading of Recommendations Assessment, Development and Evaluation) - provides a system for rating quality of evidence and strength of recommendations that is explicit, comprehensive, transparent, and pragmatic (Guyatt et al. 2008, p. 924).

⁵¹ CERQual (Confidence in the Evidence from Reviews of Qualitative research) – provides a systematic and transparent assessment of how much confidence can be placed in individual review findings from syntheses of qualitative evidence (Lewin et al. 2015, p. 15).

⁵² ConQual (Confidence of synthesized qualitative findings) – suitable for JBI meta-aggregative reviews and focuses on the certainty of the findings (Munn et al. 2014).

⁵³ This initial work (Edwards et al. 2014) was performed under the guidance of Professor Jane Noyes, an author of the original GRADE CERQual publication and member of the GRADE working group.

using a convergent approach which ‘qualitised’⁵⁴ the findings from the quantitative descriptive and non-intervention studies (Sandelowski 2000). Additionally, using a convergent segregated approach⁵⁵ where findings were also generated from quantitative experimental data, GRADE was applied and reported alongside GRADE-CerQual in the final overarching syntheses (**papers 2, 3 and 6**). Other methodologists have also started to apply their own adapted GRADE approaches to the findings from quantitative descriptive studies (WHO 2017) and MMSRs that include diverse types of evidence (Calonge et al. 2022), but these have yet to be endorsed by the GRADE working group.

In this critical commentary, I demonstrate the impact that the published works are beginning to have on practices/services. The evidence synthesis (**paper 1**) and wider findings from CoCaDS were forwarded to the Cancer Implementation Group person-centred care team and as a consequence, the recent cancer patient experience survey was adapted to include a question regarding pre-existing physical disability and its impact on their cancer experience. The findings were also presented to Breast Test Wales regarding access to and the environment for breast screening in their mobile units and as a result most mobile units now have ramps (occasionally lifts) to support disabled access. Additionally, as part of the Cardiff University MSc module in ‘Understanding cancer patient/professional perspectives’ members of the research team and a service user with experience of disability and cancer now jointly lead a seminar on disability and cancer. There are plans⁵⁶ that the findings from the evidence synthesis (**paper 6**) and ethnographic study on continence and dementia will be used to develop and deliver outputs which focus on service organisation and training staff within the acute setting.

⁵⁴ Qualitative data and ‘textual description’ of quantitative data (qualitised data), are assembled, and then pooled where possible.

⁵⁵ Synthesized quantitative results are juxtaposed alongside synthesized qualitative findings, and then findings are linked into a line of argument to produce an overall configured analysis.

⁵⁶ Evidence synthesis published September 2021 and wider NIHR report June 2022.

4.5. Strengths and limitations

The strengths of the MMSRs, that are presented in this critical commentary, are the involvement of stakeholders, additionally searching for grey literature and the assessment of the confidence/certainty across the body of evidence⁵⁷.

Another strength is the novel approach of combining an initial scoping of the evidence with a stakeholder consultation to determine the focus of the evidence synthesis based on the methodology from the EPPI-Centre (**papers 2-4 and 6**)⁵⁸. Lasserson et al. (2021) in the opening chapter of the Cochrane handbook, suggest that this is an important step as the priorities for the stakeholders in the topic area may be different than those considered to be important by the researchers. It is becoming increasingly common to engage with stakeholders⁵⁹ across all stages of the evidence synthesis process (Feldmann et al. 2019). A 2018 scoping review found 291 publications (from 2010 to 2016) in which stakeholders were involved⁶⁰ in some aspect of an evidence synthesis (Pollock et al. 2018). In considering what questions and priorities are important to different stakeholders it is hoped that the final synthesis will have improved relevance and applicability (Rees and Oliver 2017; Merner et al. 2021).

One of the criticisms of evidence syntheses that report stakeholder involvement is a lack of reporting of the details to enable replication (Merner et al. 2021). **Paper 4** describes the involvement of stakeholders in the prioritisation process using the nominal group technique and has been provided in this critical commentary for completeness. This method was chosen to create a structure and process that enabled our stakeholder group to shape the focus of our study towards an area of more importance and relevance to them, for example less obvious risks that are important as opposed to the clinical risks such as suicide, harm to others or physical deterioration. This approach has been further developed and used across the

⁵⁷ See page 38.

⁵⁸ The stakeholders across the included evidence syntheses were patients, caregivers, service managers, practitioners drawn from different occupational groups and workers from non-statutory organisations.

⁵⁹ A stakeholder is defined as “any person who uses research knowledge but whose primary role is not directly in research” (Pollock et al 2018, p. 246).

⁶⁰ Stakeholder involvement is defined as “any role or contribution of stakeholders toward the development of a review protocol, completion of any of the stages of a systematic review, or dissemination of the findings of a review” (Pollock et al. 2018 p. 246).

evidence syntheses that incorporated stakeholder involvement (**Papers 2 and 6**) I have undertaken and has been pivotal in identifying the key issues.

The MMSRs described in **papers 2-4 and 6**, all involved searching for grey literature.⁶¹ This is seen as an important but challenging component of any evidence synthesis in an attempt to locate and identify all studies relevant to the primary research question/s. Paez (2017, p. 233) comments that the inclusion of grey literature can:

Increase reviews' comprehensiveness and timeliness and foster a balanced picture of available evidence

Over the last 20 years, reviewers have considered that including grey literature within an evidence synthesis of effectiveness alongside published research has the potential to provide more accurate effect sizes and a more unbiased overall understanding of the evidence (Benzies et al. 2006; Hopewell et al. 2007). However, not much has been written with regard to publication bias and qualitative evidence although Petticrew et al. (2008) noted that systematic reviews of qualitative studies may be biased if they rely only on published papers. In an examination of the abstracts from the British Sociological Association Medical Sociology meetings in 1998 and 1999 they found that it was the qualitative research that lacked clear objectives and findings that were less likely to have been published. In examining the included studies across the evidence syntheses in these published works, it was observed that grey literature searching had identified a number of qualitative, descriptive surveys and mixed methods studies that would have otherwise been missed.⁶²

A further strength of the MMSRs was in successfully reporting the synthesis of a relative disparate body of evidence that included non-research material. As a result of this work, I am now part of the JBI Textual Evidence Methods group where I am

⁶¹ Refers to resources that are unpublished or have been published by sources that are neither commercial nor academic and can include research and non-research based material such as magazine articles, trade press articles, academic dissertations, institutional reports, fact sheets, websites, policy documents (Mahood et al. 2014; Godin et al. 2015; Paez 2017).

⁶² Identified from institutional repositories (Google search) and from the websites of key organisations (identified by the stakeholders).

involved in the writing of updated guidance for the JBI Manual of Evidence Synthesis⁶³.

A limitation of this critical commentary is that when writing the methods sections within the original published work I did not classify the methods of integration. Hong et al. (2017, p. 13) noted this to be a common problem in the reporting of MMSRs as providing such detail can “enhance the value of a review”. To rectify this within this critical commentary, I have provided the information within [appendix 3](#).

A further limitation is with the reporting of the GRADE-CerQUAL within **papers 3** published in 2015. I did not report the standard summary of findings tables within the original publication or as supplementary material. The GRADE-CerQual within **paper 3** was informed by a previous review I had undertaken (Edwards et al. 2014). Both of these reviews were informed by work of Glenton et al. (2013) who developed the original GRADE-CerQual in their review on barriers and facilitators to the implementation of lay health worker programmes to improve access to maternal and child health. The full guidance was then published in 2018, thus was not available when **paper 3** was published

⁶³ Chapter 4 (updated). Systematic review of textual evidence, narrative, expert opinion or policy. Pearson A, Jordan Z, McArthur A, Florescu S, Cooper A, Yan H, Klugarova J, Stannard D, Edwards D.

Chapter 5: Conclusions

Each of the MMSRs within this critical commentary have been through the peer review process and published in scientific journals, each with overarching syntheses that demonstrate the creation and interpretation of new knowledge (see figures 1 to 5). Additionally, in relating this work to the existing body of knowledge around vulnerabilities and the VPCM and in conceptualising how the MMSR findings fit into this model has itself generated new knowledge. Such knowledge enables us to understand the characteristics and situations that perpetuate health inequalities for vulnerable persons and can be used to improve HCPs' understanding of vulnerability within any given medical situation and hopefully improve care.

Vulnerability in relation to healthcare issues has been considered in terms of both a categorical approach based on certain individual intrinsic characteristics and a situational approach as individuals navigate the healthcare system. The link between healthcare inequalities and systematic differences in health between different groups has also been acknowledged. The use of the VPCM has provided an organising framework for this critical commentary in which I explored factors related to resource availability, relative risks, and health status. What is evident across the wider evidence base is that vulnerable populations can encounter substantial challenges navigating healthcare systems which can lead to delays in diagnosis, higher rates of morbidity and pre-mature mortality. This critical commentary has highlighted these issues, specifically for access to cancer services for adults with a physical disability and for EOL care for adults with SMI.

In relation to the VPCM, it is important to note that the majority of MMSRs in this critical commentary have identified factors relating to resource availability for vulnerable populations as they navigate the healthcare system. In generating new knowledge this critical commentary has shown that resource availability was conceptualised as interactions and/or relationships with HCPs. This is of concern as the VPCM proposes that those who lack available resources are at increased risk of negative health outcomes and can additionally increase societal costs and burden. Additionally, when caring for potentially vulnerable persons, it is crucial that HCPs

understand the unique challenges involved and that they take measures to improve the quality of their interactions so that equitable care and treatment can be provided.

The implication of this work is that using the VPCM in this way has potential value to inform healthcare practice, and policy about the opportunities and resources needed to protect the health status of vulnerable individuals. Flaskeurd and Winslow (1998) suggest that the VPCM provides an opportunity to consider clinical practice interventions with vulnerable populations. In considering these resource issues and the interplay between a relative risk and health status we can start to understand the unique challenges to implementing such interventions for vulnerable populations. When caring for potentially vulnerable persons, it is crucial that health care professionals understand the unique challenges involved and that they take measures to improve the quality of their interactions so that equitable care and treatment can be provided.

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Appendices

Appendix 1: Full publication list

2022

Edwards, D., Williams, J., Carrier, C. and Davies, D. Technologies used to facilitate remote rehabilitation of adults with deconditioning, musculoskeletal conditions, stroke, or traumatic brain injury. An umbrella review. *JBI Evidence Synthesis*. 2022; 20(8): <https://doi.org/10.11124/JBIES-21-00241>

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<https://doi.org/10.1080/09638230802052153>

Appendix 2. List of published works

The following published works are referred to throughout this critical commentary.

- Paper 1.** Edwards, D., Sakellariou, D. and Anstey, S. 2020. Barriers to, and facilitators of, access to cancer services and experiences of cancer care for adults with a physical disability: A mixed methods systematic review. *Disability and Health Journal* 13(1):100844. <https://doi.org/10.1016/j.dhjo.2019.100844>

Supplementary online material

1. <https://ars.els-cdn.com/content/image/1-s2.0-S1936657419301566-mmc1.docx>
2. <https://ars.els-cdn.com/content/image/1-s2.0-S1936657419301566-mmc2.docx>
3. <https://ars.els-cdn.com/content/image/1-s2.0-S1936657419301566-mmc3.docx>
4. <https://ars.els-cdn.com/content/image/1-s2.0-S1936657419301566-mmc4.docx>

- Paper 2.** Edwards, D., Anstey, S., Coffey, M., Gill, P., Mann, M., Meudell, A. and Hannigan B. 2021. End of life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis (the MENLOC study). *Palliative Medicine*. Sep 3;2692163211037480. <https://doi.org/10.1177/02692163211037480>

Supplementary online material

1. https://journals.sagepub.com/doi/suppl/10.1177/02692163211037480/suppl_file/sj-pdf-1-pmj-10.1177_02692163211037480.pdf
2. https://journals.sagepub.com/doi/suppl/10.1177/02692163211037480/suppl_file/sj-pdf-2-pmj-10.1177_02692163211037480.pdf
3. https://journals.sagepub.com/doi/suppl/10.1177/02692163211037480/suppl_file/sj-pdf-3-pmj-10.1177_02692163211037480.pdf
4. https://journals.sagepub.com/doi/suppl/10.1177/02692163211037480/suppl_file/sj-pdf-4-pmj-10.1177_02692163211037480.pdf
5. https://journals.sagepub.com/doi/suppl/10.1177/02692163211037480/suppl_file/sj-pdf-5-pmj-10.1177_02692163211037480.pdf

- Paper 3.** Edwards, D., Evans, N., Gillen, E., Longo, M., Prymachuk, S., Trainor, G. and Hannigan, B. 2015. What do we know about the risks for young people moving into, through and out of inpatient mental health care? Findings from an evidence synthesis. *Child and Adolescent Psychiatry and Mental Health* (12)9:55. <https://doi.org/10.1186/s13034-015-0087-y>.

- Paper 4.** Evans, N., Hannigan, B., Prymachuk, S., Gillen, E., Edwards, D., Longo, M., Trainor, G. and Hathway, F. 2017. Using the nominal group technique to involve young people in an evidence synthesis which explored 'risk' in inpatient mental healthcare. *Research Involvement and Engagement* 3:16. <https://doi.org/10.1186/s40900-017-0069-8>.

Paper 5. Edwards, D., Carrier, J. and Hopkinson, J. 2017. Assistance at mealtimes in hospital settings and rehabilitation units for patients (>65years) from the perspective of patients, families and healthcare professionals: A mixed methods systematic review. *International Journal of Nursing Studies* 69(4):100-118.
<https://doi.org/10.1016/j.ijnurstu.2017.01.013>

Supplementary online material

1. <https://ars.els-cdn.com/content/image/1-s2.0-S0020748917300263-mmc1.docx>
2. <https://ars.els-cdn.com/content/image/1-s2.0-S0020748917300263-mmc2.docx>
3. <https://ars.els-cdn.com/content/image/1-s2.0-S0020748917300263-mmc3.docx>

Paper 6: Edwards, DJ., Harden, J., Featherstone, K. and Jones, A. 2021. Understanding how to facilitate continence for people with dementia in acute hospital settings: A mixed methods systematic review and thematic synthesis. *Systematic Reviews* 10, 199 (2021).
<https://doi.org/10.1186/s13643-021-01743-0>

Supplementary online material

1. https://static-content.springer.com/esm/art%3A10.1186%2Fs13643-021-01743-0/MediaObjects/13643_2021_1743_MOESM1_ESM.docx
2. https://static-content.springer.com/esm/art%3A10.1186%2Fs13643-021-01743-0/MediaObjects/13643_2021_1743_MOESM2_ESM.docx
3. https://static-content.springer.com/esm/art%3A10.1186%2Fs13643-021-01743-0/MediaObjects/13643_2021_1743_MOESM3_ESM.docx
4. https://static-content.springer.com/esm/art%3A10.1186%2Fs13643-021-01743-0/MediaObjects/13643_2021_1743_MOESM4_ESM.docx

Appendix 3: Key features of the mixed methods systematic reviews included in the critical commentary

Published work	Included study designs	Methodology			
		Guidance	Stakeholder involvement	Integration	Confidence / Certainty
Paper 1 Adults with a physical disability	Qualitative Quantitative descriptive	EPPI	No	Convergent integrated ⁶⁴	Adapted GRADE-CERQual
Paper 2 Adults with severe mental illness	Qualitative studies Quantitative – descriptive studies Quantitative - observational studies Mixed methods studies UK only grey literature Non-research materials	EPPI	Yes	Convergent segregated ⁶⁵	Adapted GRADE-CERQual GRADE
Paper 3 Paper 4 Young people with complex mental health needs	Qualitative studies Quantitative – descriptive studies Quantitative – experimental studies Mixed methods studies UK only grey literature Non-research material	EPPI	Yes	Convergent segregated	Adapted GRADE-CERQual GRADE
Paper 5 Older adults (>65 years)	Qualitative studies Quantitative – descriptive studies Quantitative - observational studies Mixed methods studies	JB ⁶⁶	No	Segregated ⁶⁷	JB Grades of recommendation
Paper 6 Adults with dementia	Qualitative studies Quantitative – descriptive studies Quantitative - observational studies UK only grey literature / Non research material	EPPI	Yes	Convergent segregated	Adapted GRADE-CERQual GRADE

Key: EPPI: Evidence for Policy and Practice Information and Co-ordinating Centre

⁶⁴ Convergent integrated – Quantitative data and ‘textual description’ of quantitative data (quantized data), are assembled, and then pooled where possible

⁶⁵ Convergent segregated – Juxtapose synthesized quantitative results with synthesized qualitative findings, and then organise or link the results and findings into a line of argument to produce an overall configured analysis

⁶⁶ Methodology as per The JBI Reviewers’ Manual 2014 (Pearson et al. 2014)

⁶⁷ A segregated approach to mixed method synthesis which consists of separate syntheses of each component method of the review. The initial findings of the quantitative synthesis are then translated into qualitative themes and pooled with the findings of the initial qualitative synthesis (Pearson et al. 2014)

Appendix 4: CERQual and GRADE summary of findings for paper 3

Summary of review findings	CERQual or GRADE rating
Dislocation: normal life	
Everyday life and interactions in hospital Views and experiences were reported in rich detail and young people and health care professionals described boredom, stringent ward rules and routines, and a lack of opportunity for everyday interactions	High Confidence
Missing out on life outside and transition home Feeling separated from life outside and the subsequent difficulties experienced on returning home were identified as pressing issues by some young people and healthcare professionals	High Confidence
Dislocation: identity	
Mental health problems as identity-changing Young people with eating disorders talked about mental health problems eroding their identities Young people with eating disorders talked about the experience of not being treated as individuals	Moderate Confidence Low Confidence
Responding to threats to identity For other young people it was a struggle to manage threats to the sense of self during admission and treatment	Low Confidence
Dislocation: friends	
Relationships with young people outside hospital	
Difficulties (and ambivalence) young people can experience in maintaining home friendships at a distance	High Confidence
Difficulties in reconnecting with their friends after discharge	High Confidence

Relationships with young people in hospital	
Evidence was found pointing to young people's positive views of being with others in a similar position during hospital care and treatment, in terms of mutual support and companionship	High Confidence
Young people also spoke of the negative aspects of living with other young people with mental health	High Confidence
Some parents were found to be concerned about their children's sharing of living space with other vulnerable people and at least some young people expressed ambivalence (and even fear) in their relationships with other inpatients	Low Confidence
Dislocation: stigma	
Young people's experiences during admission	
Young people felt that stigmatising experiences can occur as a result of being admitted, as well as during their inpatient stay	Moderate Confidence
Being with similar young people can also lead to feelings of acceptance, in contrast with the experience of being rejected in the community	Low Confidence
Young people's experiences after discharge	
Young people felt that stigmatising experiences can occur at discharge	Low Confidence
No intervention studies were found evaluating actions to mitigate the risks of stigma or discrimination to young people admitted to mental health hospital	
Dislocation: education	
Education provision and facilities	
Health care professionals, parents and young people all recognise the importance of educational provision with appropriate facilities for young people in inpatient CAMHS	High Confidence
Smaller class sizes	
Utilising a multiclass format with specialist teaching have been shown in a study involving young people in a RTC in the USA be effective in increasing the amount of work young people are able to produce while in hospital	GRADE Low Quality

In the UK, education is provided as standard across inpatient units, but in a majority of hospitals only core National Curriculum subjects are taught	High Confidence
Quality of inpatient education	
Within units in the UK, varying teacher/student ratios are found in NHS and non-NHS units	High Confidence
Good (but not universally so) relations between parents and teachers have been reported	Low Confidence
Dislocation: families	
Impact on family relationships	
While on an inpatient unit, young people often feel homesickness	High Confidence
While on an inpatient unit, experience a range of negative experiences	Moderate Confidence
Associations between family connectedness and post-discharge depression and suicidal ideation have been reported	Low Confidence
Some family members need additional support during their children's admission	Low Confidence
Family involvement	
Young people whose parents do get involved make significant improvements across a range of treatment and post-discharge outcomes but health professionals report that a number of obstacles exist to enable this to take place	Low Confidence
Training inpatient staff working with young people and their families through the use of role plays or mindfulness did not have a significant impact on the family-friendliness of the admission process	GRADE Low Quality
Maintaining contact with families	
A particular risk of family dislocation is reported in instances where young people are admitted to hospitals located far from home, in terms of keeping in touch and cost	High Confidence
The quality of care at inpatient units is considered to be more important than the distance from the hospital to the family home	Moderate Confidence
Some young people also appreciated being away from the home environment	Low Confidence

Contagion	
<p>Experiences of contagion</p> <p>Health professionals and parents have concerns about young people acquiring unhelpful, destructive behaviours while they are inpatients</p> <p>Young people with eating disorders very quickly copy the behaviour of those around them with the same condition</p>	<p>Moderate Confidence</p> <p>Moderate Confidence</p>
Evidence of contagion	
<p>There is mixed evidence of recorded contagion in inpatient mental health facilities for young people with no fixed definition of what constitutes 'contagion'</p>	<p>Low Confidence</p>

Appendix 5: CERQual summary of findings for paper 6

Review Finding	Assessment of Methodological Limitations	Assessment of Relevance	Assessment of Coherence	Assessment of Adequacy	Overall CERQual Assessment of Confidence
Studies Contributing to the Review Finding					
Theme 1: Communication that is dignified, person centred and respectful					
<i>Communicating in a dignified way</i>					
1. PLWD & their carers find talking about incontinence distressing and embarrassing Studies 2, 3,4	No or very minor methodological limitations (two studies had no concerns and one study had minor methodological limitations)	Moderate concerns about relevance (studies were from two countries only which were USA and Australia UK (covering two continents))	Minor concerns about coherence (data reasonably consistent within and across all studies)	Moderate concerns about adequacy (with all studies having offering thin data)	Moderate confidence
2. HCPs to build trust and rapport through using humour, having appropriate knowledge and skills by speaking quietly and keeping incontinence issues secret Studies 2, 3,4	No or very minor methodological limitations (two studies had no concerns and one study had minor methodological limitations)	Moderate concerns about relevance (studies were from two countries only which were USA and Australia (covering two continents) but not the UK)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Moderate concerns about adequacy (with all studies having offering thin data)	Moderate confidence
<i>The attitudes of HCPs towards continence and continence care</i>					
3. HCPs often ignore toileting requests or avoid routine toileting citing being busy or being	No or very minor methodological limitations (one study had no concerns	Moderate concerns about relevance (as	Moderate concerns about	Moderate concerns about adequacy one	Moderate confidence

uncomfortable with or disinterested in toileting Studies 2, 14	and one study had minor methodological limitations)	the studies were from two countries only which were Malta and the USA (covering two continents) but not the UK	coherence (data more varied and this finding is over-simplified	study offering rich data and one study with thin data)	
4. Staff in acute settings do not consistently promote continence Study 14	Minor methodological limitations	Serious concerns about relevance as one study from one country which was Malta	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
5. HCPs having respect building relationships and using appropriate language Study 2	Minor methodological limitations	Serious concerns about relevance as one study from one country which was USA	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
6. Interpersonal and communication skills are important and should be a focus of education programs Non research [87,88]					Ungraded
<i>The importance of non- verbal cues</i>					
7. PLWD are not always able to recognise and communicate that they need to go to the toilet or indicate that they need assistance and they use a variety of non-verbal cues	Minor methodological limitations (four studies had minor methodological limitations)	Moderate concerns about relevance (as the studies were from three countries only	Minor concerns about coherence (data reasonably	Minor concerns about adequacy (all studies offering rich data)	High confidence

Studies 1, 2, 3, 4, 5, 6, 7, 10, 11, 12 Non research [10,80–84,86,88]		which were Taiwan, Australia and the USA (covering three continents) but not the UK	consistent within and across all studies)		
8. HCPs checking PLWD awareness of communication techniques including non-verbal cues through communicating with the family Studies, 2, 13	Minor methodological limitations (two studies had minor methodological limitations)	Moderate concerns about relevance (as the studies were from two countries only which were Malta and the UK (covering one continents)	Moderate concerns about coherence (data more varied and this finding is over-simplified)	Moderate concerns about adequacy one study offering rich data and one study with thin data)	Moderate confidence
9. HCPs being able to recognize the non-verbal signals, body language, facial expressions, behaviours and signs that PLWD use to communicate that they need to go toilet is crucial and this should be a focus education programs for new staff Studies 2, 12 Non research [80–82]	No or very minor methodological limitations (one study had no concerns and one study had minor methodological limitations)	Moderate concerns about relevance (as the studies were from two countries only which were Taiwan and the USA (covering two continents) but not the UK	Minor concerns about coherence (data reasonably consistent within and across all studies)	Moderate concerns about adequacy one study offering rich data and one study with thin data)	Moderate confidence
<i>Finding the appropriate words and symbols to describe the toilet</i>					
10. Finding out what words or phrases that PLWD use for describing the toilet is seen as important Study 7	No concerns	Serious concerns about relevance as one study from one country	Serious concerns about coherence (only one	Serious concerns about adequacy (only one study offering data)	Very Low confidence

Non research [80,82–84]		which was Australia	study offering data)		
11. People living with moderate dementia preferred the word toilet compared to those with normal cognition and those with advanced dementia preferred the international symbol for toilet compared to those with mild or normal cognition Study 7	No concerns	Serious concerns about relevance as one study from one country which was Australia	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
Strategies for improving communication					
12. HCPs introducing themselves and seeking PLWD approval before performing tasks Study 4	Minor methodological limitations	Serious concerns about relevance as one study from one country which was Australia	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
13. A range of strategies have been identified that include getting to know the PLWD & how they communicate and manage their continence, communicating with the family, prompting, seeing the person has an individual, and checking HCPs communication skills Studies 4, 13 Non research [10,81–84]	No or very minor methodological limitations (one study had no concerns and one study had minor methodological limitations)	Moderate concerns about relevance (as the studies were from two countries only which were UK and the USA (covering two continents))	Moderate concerns about coherence (data more varied and this finding is over-simplified)	Moderate concerns about adequacy two studies offering thin data)	Moderate confidence
Theme 2: Communication during outpatient appointments					
<i>Presence of PLWD during outpatient consultations</i>					

14. Caregivers felt having the PLWD with them during outpatient consultations could cause unnecessary anxiety Study 1	No concerns	Serious concerns about relevance as one study from one country which was USA	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
15. Caregivers felt having the PLWD with them during outpatient consultations would allow greater cooperation with management strategies Study 1	No concerns	Serious concerns about relevance as one study from one country which was USA	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
16. HCPs felt it was important that PLWD were present at appointments Study 1	No concerns	Serious concerns about relevance as one study from one country which was USA	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
<i>Initiating conversations during outpatient consultations</i>					
17. Uncertainty over who should initiate conversations during consultations Study 3	No concerns	Serious concerns about relevance as one study from one country which was USA	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence
18. HCPs suggested developing a pre-visit checklist to prompt conversation during consultations Study 3	No concerns	Serious concerns about relevance as one study from	Serious concerns about coherence (only one	Serious concerns about adequacy (only one study offering data)	Very Low confidence

		one country which was USA	study offering data)		
<i>The language of incontinence during outpatient consultations</i>					
19. Incontinence and management options are often explained in terms that caregiver find difficult to understand. Studies 1, 3	No concerns	Serious concerns about relevance as two studies representing one country was which USA contributed to this finding	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (two studies with rich data)	Low confidence
20. Caregivers and HCPs suggested a variety of types of written information resources could be provided for the caregivers Studies 1, 3	No concerns	Serious concerns about relevance as two studies representing one country was which USA contributed to this finding	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (two studies with rich data)	Low confidence
Theme 3: Delivering individualised continence care					
<i>Importance of individualised continence care</i>					
21. Targeted and individualised/person centred continence care that is established after a thorough assessment has taken place is seen as important Non research [10,33,78,82,85,87–89]					Ungraded

22. Individualized continence care is about what is best for the PLWD and avoiding harm and about promoting autonomy and independent living Non research [10]					Ungraded
<i>Components of individualised care planning</i>					
23. Individualised care planning should consider the needs of both PLWD and their caregivers and involve multi-components exploring both day-time and night care of incontinence are helpful in addressing incontinence in the home care setting Non research [10,33,78,85–87]					Ungraded
24. An intervention that involved individual treatment strategies delivered by an occupational therapist and designed to enhance the caregiver's ability to problem solve about their environment. A post intervention survey reported that this approach enabled caregivers to develop effective solutions to situations they considered problematic which included toileting Studies 10,11	Minor methodological limitations (two studies had minor methodological limitations)	Serious concerns about relevance as two studies representing one country was which USA contributed to this finding	Minor concerns about coherence (data reasonably consistent within and across all studies)	Moderate concerns about adequacy (two studies with thin data)	Low confidence
<i>Health care professionals and caregivers working in partnership</i>					
25. It is important that HCPs and caregivers work together to deliver					Ungraded

individualized/person centred continence care Non research [78,82,85,86]					
<i>Establishing a toileting routine within the home environment</i>					
26. The importance of developing a regular toileting schedule was highlighted by caregivers Study 10 Non research [10]	Minor methodological limitations	Serious concerns about relevance as one study from one country which was USA	Serious concerns about coherence (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very Low confidence

Key: HCP: healthcare professionals; PLWD: people living with dementia