An exploration of the association between literacy and mental health care and outcomes.

Lucy Hunn

Doctorate in Clinical Psychology

University of East Anglia

Faculty of Medicine and Health Sciences

Supervisor: Dr Bonnie Teague

Secondary Supervisor: Dr Paul Fisher

Submission date: 1st March 2022

Thesis portfolio word count:27,997

Candidate registration number: 100261075

Abstract

Purpose: Prior research has suggested a relationship between literacy difficulties and poorer physical health outcomes. Yet there has been far less attention paid to the impact of literacy difficulties on mental health. The overall aim of this thesis portfolio was to explore the association between literacy difficulties in adults and mental health outcomes and practice considerations.

Design: A systematic review of the literature was used to establish the reported relationship between literacy abilities and mental health outcomes. A narrative synthesis drew conclusions from the literature around this relationship and the associated mediating factors. An empirical research project used semi-structured interviews with mental health clinicians to explore qualitatively how the relationship between literacy and mental health may impact on an individual's access to, and experience of mental health services. This research had a focus on how practitioners view person-centred care in people with literacy difficulties.

Results: The systematic review suggests that there is a relationship between poorer literacy levels and poorer mental health outcomes across a range of countries and mental health presentations. The narrative synthesis also identified potential mediating factors within this association, including age, gender, education level, and poverty. Within the empirical research project, five superordinate themes were extracted from the nine interviews: Intersectionality, clinician attitude, humanistic approach, service provision, and social inequality.

Conclusions: The findings from this portfolio indicate that literacy is an important social determinant of mental health, which has significant implications for clinical practice. It also highlights the potential impact of society's views of those with literacy difficulties and the associated internalised stigma and social inequalities. Furthermore, it demonstrates how clinician awareness and responsiveness to literacy difficulties can help support the delivery of person-centred care in line with current NHS priorities.

Access Condition and Agreement

Each deposit in UEA Digital Repository is protected by copyright and other intellectual property rights, and duplication or sale of all or part of any of the Data Collections is not permitted, except that material may be duplicated by you for your research use or for educational purposes in electronic or print form. You must obtain permission from the copyright holder, usually the author, for any other use. Exceptions only apply where a deposit may be explicitly provided under a stated licence, such as a Creative Commons licence or Open Government licence.

Electronic or print copies may not be offered, whether for sale or otherwise to anyone, unless explicitly stated under a Creative Commons or Open Government license. Unauthorised reproduction, editing or reformatting for resale purposes is explicitly prohibited (except where approved by the copyright holder themselves) and UEA reserves the right to take immediate ‘take down’ action on behalf of the copyright and/or rights holder if this Access condition of the UEA Digital Repository is breached. Any material in this database has been supplied on the understanding that it is copyright material and that no quotation from the material may be published without proper acknowledgement.

List of contents

List of tables

Chapter One. Introduction to the thesis portfolio

None

Chapter Two. Systematic Review

Chapter Three. Bridging Chapter

None

Chapter Four. Empirical Paper

Chapter Five. Additional Methods

Chapter Six Extended Discussion and Critical Evaluation

None

List of Appendices

Acknowledgments

I would like to thank my research supervisor, Bonnie Teague, for sharing her expertise with me and developing me from a novice researcher into someone who has been able to complete a portfolio of research. Her continual enthusiasm and encouragement has been essential for my motivation throughout the last four years. Thanks also goes to my secondary supervisor, Paul Fisher, for his valuable input into the completion of this thesis portfolio. I would like to give a very special thanks to the co-production team from my empirical research project, without whom this research wouldn't have happened. Their input and passion was essential for driving forward the project and was an inspiration to me as both a clinician and a researcher. I would also like to thank the participants from my empirical research project who gave up their time to share their experiences and deepen our understanding of this complex area.

I also could not have completed this research without the love and support of my family and friends. To my husband for being my biggest cheerleader and his ability to keep the family afloat when the demands of doctoral training and the thesis have overtaken. To my parents for all the childcare that has enabled me to be able to complete the research. But most of all thank you to my son, Levi. Despite being the ultimate sleep thief, and thus perhaps making this research even more challenging, you are always an inspiration to me and the motivation I've needed at times. You have also forced me to have a work life balance which inevitably has made me more productive and maintained my general wellbeing.

Chapter One

Introduction to thesis portfolio

Introduction to the thesis portfolio

Valtin et al. (2016, p.3) define literacy as “the ability to read and write at a level whereby individuals can effectively understand and use written communication in all media”. Literacy is therefore important to support many of our basic tasks of daily living as well as education and employment, and when there are literacy difficulties the impact can be vast. The National Literacy Trust highlight the functional impact of low literacy throughout the lifespan “As a child they won't be able to succeed at school, as a young adult they will be locked out of the job market, and as a parent they won't be able to support their own child's learning. This intergenerational cycle makes social mobility and a fairer society more difficult.” (McGuire, 2022). The term ‘Literacy difficulties’ are a holistic description of when an individual’s ability to read, write and communicate may negatively impact on their day-to-day living and interactions. This may include core elements of daily functioning such as being unable to read letters, understand medication or other safety instructions, or signing forms (Cree et al., 2012). The term ‘functionally illiterate’, has been used to describe people with literacy difficulties, however this does not have a precise definition and has been found to have negative connotations (Vágvölgyi et al., 2016). This portfolio will therefore be referring to ‘literacy difficulties’.

The most recent literacy statistics collected in England estimated there to be 7.1 million adults (1 in 6) considered as having ‘very poor literacy skills’ (Department for Business Innovation & Skills, 2015). This means that these individuals may be able to understand short simple texts on topics they are familiar with, but that gaining information from unfamiliar sources, or on unfamiliar topics, may cause difficulties. This survey found higher numbers of literacy difficulties in younger adult cohorts (aged 16-24) compared to older adult cohorts. This is the opposite to other European countries where younger cohorts were frequently found to have higher abilities. Therefore, this survey would suggest that within England the levels of literacy difficulties are increasing, and thus it is an area that needs growing attention.

In order to understand the impact of literacy difficulties it is important to recognise why someone might have literacy difficulties. The most common causes of literacy difficulties in adults are: parents with little formal schooling, lack of access to books within the home, lack of emphasis on the importance of reading, social economic or cultural adversity, and learning disabilities, such as dysorthographia and dyslexia (Lal, 2015). This list shows that there are a variety of developmental, social, and environmental reasons why an individual may not develop their literacy skills in line with their peers through no fault of their own. It also identifies that factors related to social class are likely to influence an individual's literacy skills. This is likely to be a perpetuating factor that creates inter-generational literacy difficulties. Whilst literacy alone cannot guarantee social mobility (movement between social classes), research provides evidence to support the idea that literacy is an important factor within our modern digital economy for contributing towards positive social mobility (Levy et al., 2014).

Given the significant impact of literacy difficulties on holistic tasks of daily living and social economic status, it is perhaps unsurprising that literacy difficulties have been associated with poorer outcomes with regard to employment, health, and risks of criminal offending (Morrisroe, 2014). Sentell and Halpin (2006) found that literacy was an important factor in health disparities which may sometimes be mistakenly attributed to other factors, such as race and education. They argued that literacy could be a powerful avenue to explore in order to reduce health inequalities. Easton et al. (2013) suggest that the stigma associated with poor literacy may impact on mental wellbeing due to its effect on self-exclusion from social participation and anxiety around revealing difficulties with literacy. Given that UK legislation (Social Care Act, 2012) calls for a parity of esteem between physical health and mental health, there is a need to expand the literature to understand the role that literacy plays in mental health outcomes as well as physical health outcomes.

Health literacy is a term that has become more widespread in recent years. It is defined by the World Health Organisation as ‘the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health’ (WHO, 2015, p. 12). With this has come the recognition that information provided to the general public about health is often not accessible or understandable to many. The evidence shows that poor health literacy is associated with poorer health outcomes and higher use of health care services, and it is also an important determinant of health inequalities (Heijmans et al., 2015). Similarly, the phrase ‘Mental Health Literacy’ has been defined as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm et al, 1997, p.1). Whilst both these concepts are impacted by an individual's general literacy skills (their ability to read and write) they are distinct concepts which will not be covered in this portfolio. The core purpose of this portfolio is to look at the broader aspect of reading and writing literacy, rather than application of these core skills to gain health knowledge.

This portfolio aims to look at the relationship between literacy, mental health outcomes, and interactions with mental health services. Chapter two presents a novel systematic review conducted to synthesise the current literature available that assesses the relationship between literacy and mental health globally. A narrative synthesis is utilised to summarise the findings in a meaningful way.

Chapter three provides a concise bridging chapter linking the systematic review and the empirical paper, recognising the research gaps and addressing how we can add to the knowledge base in literacy and mental health research.

Chapter four of this portfolio is an empirical paper. This empirical research project uses co-production methodology to explore clinicians' experiences and views on supporting individuals with literacy difficulties within mental health services, specifically understanding how person-centred care is delivered in this population. Interviews were carried out with clinicians from one mental health organisation and thematic analysis (TA) was used to identify themes arising from the data. Five superordinate themes were identified, each with their own subordinate themes.

Chapter five provides information on additional methods used within the empirical research project. It provides a rationale for the epistemological stance of the research and highlights the use of co-production throughout the empirical research project. It also details the analysis process in more depth and provides evidence of how quality was maintained throughout the project.

Finally, chapter six provides a discussion and critical evaluation of the whole portfolio and discusses the theoretical and clinical relevance of the research presented. This chapter also includes personal reflections of the researcher on the experience of conducting the research included in the portfolio.

The systematic review in chapter two and the empirical paper in chapter four have both been written for publication and have therefore been formatted in accordance with specified journal publication guidelines available in the appendices.

Chapter Two

Systematic Review

Systematic review paper prepared for submission to ‘Mental Health and Social Inclusion’ Journal

Author guidelines can be found in Appendix A

Literacy and Mental Health Across the Globe: A Systematic Review

Word count: 5105 without tables

Purpose: 14% of the global population has little or no literacy. Literacy skills impact on daily functioning and have been shown to impact on social outcomes. Whilst there has been research examining the potential association between literacy and mental health outcomes in specific populations, there has been no systematic review of this literature to date.

Design/Methodology/Approach: A systematic review was carried out using Embase, PsycINFO and PubMed to identify relevant papers that measured both literacy and mental health. Data relating to the association between literacy and mental health were extracted. The papers included were assessed for quality using a bespoke quality rating tool. A narrative synthesis describes the findings.

Findings: Nineteen studies from across nine countries were included in the analysis. Seventeen studies showed a significant association between literacy and mental health, those with lower literacy had greater mental health difficulties. Some papers reported factors that interacted with this association, such as age, gender, poverty, and years of education.

Originality/Value: This is the first systematic review to look at the global picture of literacy and mental health. It suggests there is a relationship between literacy abilities and mental health outcomes, highlighting the importance of healthcare professionals and services including identification of literacy needs within routine mental health practice.

Key words: Literacy, Illiterate, education status, Mental Health, Mental illness, Prevalence

Paper type: Literature review

Introduction

Literacy is the ability to read and write to interact and communicate with the world around us (National Literacy Trust, NLT, https://literacytrust.org.uk/information/what-is-literacy). The basic reading skills required to become "literate" do not develop naturally; we learn to use our brain to recognise images in order to identify written letters and words (Wolf and Stoodley, 2008). Despite rising literacy rates over the past 50 years, there are still an estimated 773 million illiterate adults globally (UNESCO, 2021). Gilbert *et al*., (2018) describe how lacking literacy skills holds a person back at all stages of life. Literacy is a human right that empowers and enables individuals to participate more fully in their own life and society (Murray, 2021). The '2030 Agenda for Sustainable Development' states the UN are committed to advancing literacy as part of their strategic goal of good health and wellbeing (Department of Economic and Social Affairs, 2016).

There is an association between lower literacy and negative health outcomes (Berkman *et al.*,2004). Lower literacy is related to an increased risk of hospitalisation (Baker *et al.*, 2002), poorer global health status and some chronic diseases (DeWalt *et al.*, 2004), and shorter life expectancy (Gilbert *et al.*, 2018). Research also suggests an association between literacy difficulties and mental health. The existing literature largely focuses on reading difficulties in children, where associations have been documented with internalizing (Arnold *et al.*, 2005) and externalizing (Snowling *et al.*, 2007) difficulties. Morgan, Farkas, and Wu (2012) found poorer readers reported greater feelings of anger, sadness, loneliness, anxiety, distractibility, and being unpopular. They propose that early reading failure results in negative effects on children's socioemotional adjustment. Boyes *et al.,* (2016) suggest the relationship between reading difficulties and mental health in children may be ameliorated or exacerbated by risk or resilience-promoting factors. One review of reading outcomes found that poor readers were at moderate risk for experiencing internalising problems, anxiety and depression, compared to typical readers across the lifespan (Francis *et al.*, 2019). Sentell and Shumway (2003) found that adults with a mental health problem had lower functional literacy levels, even after controlling for education level, demographic, and socioeconomic factors. In an older adult population, Zhang (2021) found low literacy increased anxiety and loneliness, and decreased happiness.

Beyond individuals, literacy has a broader socioeconomic and developmental context. Literacy rates are lower in developing countries (Roser and Ortiz-Ospina, 2016) and those with a history of conflict (Zua, 2021). UNESCO's latest global analysis of literacy rates shows South Sudan has the lowest global population literacy rate (27%). There is also a gender gap in literacy abilities; two thirds of the global illiterate population are female, perhaps linked to cultural narratives around female school access (UNESCO, 2019). This gender difference in literacy abilities appears static with little change over time in male:female ratios (UNESCO, 2017). Research by Cree, Kay, and Steward (2012) identifies lack of literacy as one of the most overlooked socio-economic issues globally, with the most marginalised and poorer populations being impacted most by lack of literacy skills (UNICEF, 2015). They recognise that without literacy skills individuals risk becoming trapped in poverty due to limited opportunities for employment or income generation. Morrisroe (2014) suggests those with poorer literacy have poorer social outcomes, including higher criminal offence rates and negative impacts on employment. It is estimated that the cost of illiteracy to the global economy is £800 billion, due to the burden on healthcare systems and welfare payments (World Literacy Foundation, 2018).

The literature suggests that there is a relationship between literacy and mental health outcomes, however to our knowledge, there has been no systematic review of the literature to assess this relationship between general mental health and overall literacy abilities in adult populations. A systematic review will develop the existing literature by providing a thorough summary of the available research. Understanding this relationship better will help develop future research and ways of working to best support individuals with literacy difficulties within mental health practices.

Methods

To explore the association between literacy and mental health a systematic review was undertaken. The review protocol was listed on the international prospective register of systematic reviews (PROSPERO) in May 2021.

Search strategy

A systematic review of the literature was completed using Embase, PsycINFO and PubMed on the 21st of June 2021. Search terms were refined following scoping searches and identification of relevant keywords. Three search strings were utilised, 1) Literacy, 2) Mental health outcomes, and 3) Study type. Full search terms can be found in Appendix B.

Inclusion criteria:

- Full text available in English
- Study participants over 18 years of age
- Include a measure of literacy *and* mental health

Exclusion criteria:

- Health conditions that directly impact on cognitive functioning, such as developmental disorders and dementia

Initial abstract review was used to assess if the returned searches contained papers looking at the specific relationship between mental health and literacy. There were two independent reviewers of abstracts and any disagreements around inclusion of a paper were resolved by a third-party reviewer. Each article excluded was coded with a reason for exclusion.

The initial search returned 1823 papers. After initial screening procedures (see Illustration 1. for PRISMA diagram), 311 papers had a full text review for eligibility. Following a review of the results, searches were further limited to papers published in the last 10 years due to changes in access to information as a result of increased global availability of the internet and the effect this may have on results of the review. Nineteen studies met the final study criteria and were included in the analysis.

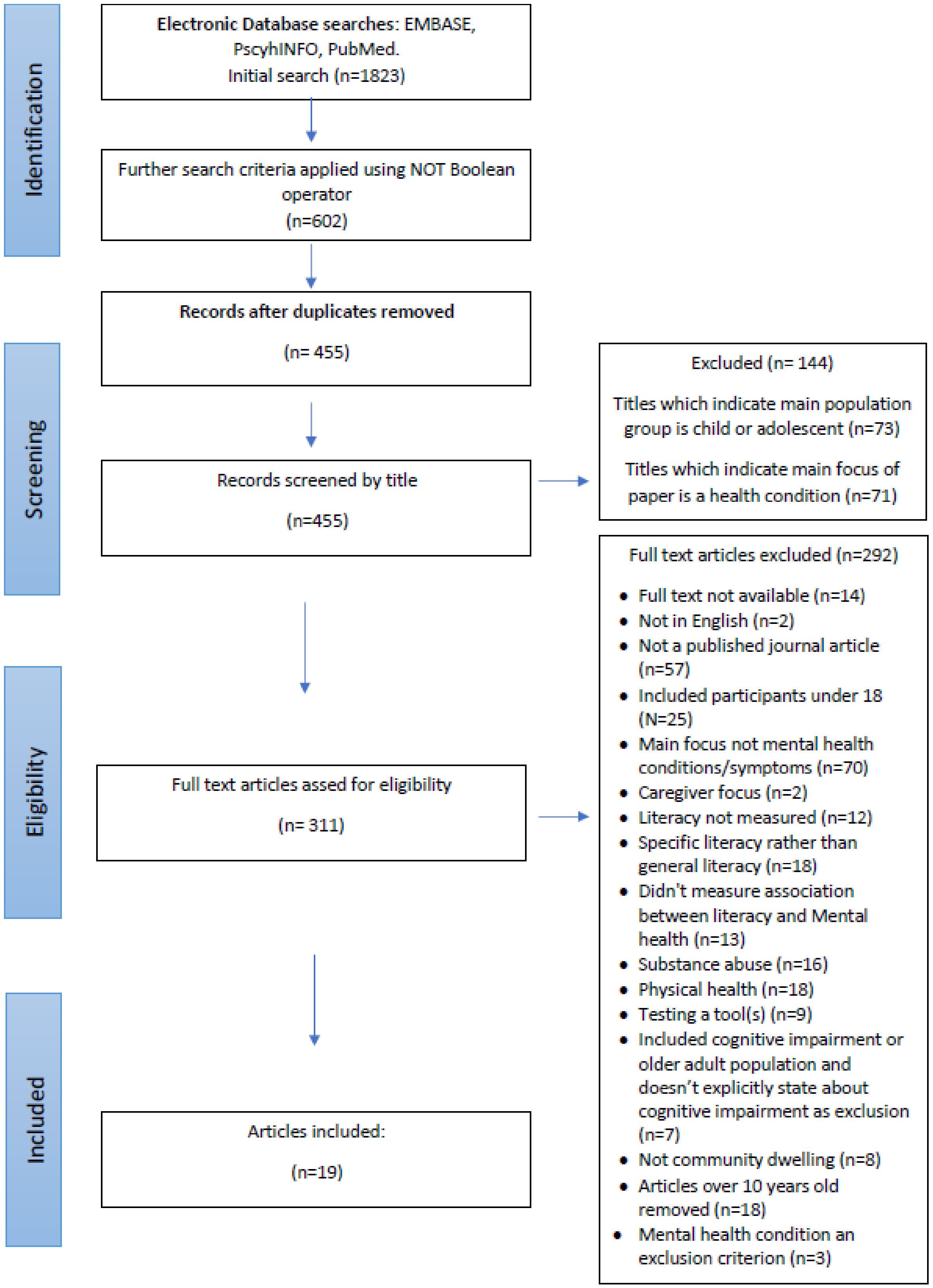


Illustration 1: PRISMA diagram

Data extraction

A data extraction tool was developed by the authors which detailed the study characteristics, including demographic information, measure of literacy, mental health measure, and main outcomes. Only outcomes specifically relating to the association between literacy and mental health were included in this review.

Quality assessment

A bespoke quality assessment tool (Appendix C), influenced by existing tools such as AXIS (Downes *et al*., 2016), Critical Appraisal Skills Programme (CASP, 2018) cohort study checklist and The Newcastle-Ottawa Scale (Wells *et al*., 2000), was developed to reflect the relevant factors when considering risk of bias and quality. This tool rated 5 areas on a scale of 1-10: study question, sample, recruitment, validity, and analysis. Higher scores represent higher quality papers. The first author independently rated each paper with the second author (BT) evaluating a third of the papers to substantiate the quality ratings. A Kappa score of 0.89 was calculated indicating ‘Almost perfect agreement’. Papers that scored 9-10 were considered good quality, those scoring 7-8 were considered fair quality, and those scoring 5-6 were considered to be low quality. Any papers scoring 4 and below were considered as very poor and unacceptable for inclusion.

Results

Quality ratings

All papers included in this review scored above the minimum quality rating to be included. Overall scores awarded for quality can be found in Table 2.1 (see Appendix D for a breakdown of the quality scores). Two studies were considered to be low quality (Basnet *et al.,* 2018; Boakye-Yiadom *et al.,* 2015), eight were considered to be fair quality (Baral and Bhagawati, 2019; Firdaus, 2017; Fortes *et al.,*2011; Hassandzadeh *et al.,*2018; Lincoln *et al.,* 2021; Mubeen *et al.*,2012; Rong *et al*., 2019; Safi and Tariq, 2013), and nine were considered good quality (Charoensakulchai *et al*., 2019; Farooq *et al*., 2019; Gupta *et al.*, 2020; Kohli *et al.*, 2013; Liu *et al.*, 2013; Manandhar *et al.*, 2019; Mathias *et al.*, 2015; Nguyen *et al.*,2017; Simkhada *et al.*,2018) . The most common reasons for papers being marked down on their quality rating were a lack of clear inclusion and exclusion criteria, and lack of a sample size justification.

Study characteristics

Table 2.1 provides an overview of the characteristics of the 19 studies included in the final review. Across the studies a total of 1,949,859 participants were included (range 154 - 1,909,205) from across nine countries (USA, China, Nepal, Thailand, Iran, India, Ghana, Pakistan, and Brazil). The literacy prevalence rates reported varied between 6% to 86% of participants reporting no literacy (mean rate of 33%).

Table 2.2 provides details of mental health outcomes included in the papers and how they were measured. The mental health outcomes included in the review comprised of depression (68%), anxiety (21%), post-traumatic stress disorder (PTSD, 11 %), schizophrenia (11%), bipolar disorder (5%), mental health status (5%), mental wellbeing (5%), and general measures of wellbeing or common mental disorder symptoms (16%). Some papers looked at multiple mental health outcomes. All studies utilised a validated way of measuring mental health outcomes.

There was not a standardised approach to measuring literacy in the studies reviewed (Table 2.2). Twelve of the papers (63%) used years of education as a proxy for literacy (Baral and Bhagawati, 2019; Basnet *et al*., 2018; Boakye-Yiadom *et al.*, 2015; Charoensakulchai *et al*., 2019; Farooq *et al.*, 2019; Hassandzadeh *et al*., 2018; Kohli *et al.*, 2013; Manandhar *et al*., 2019; Mathias *et al*., 2015; Mubeen *et al*., 2012; Rong et al., 2019; Safi and Tariq, 2013).

Three papers used a specific test of literacy (Lincoln *et al.*, 2021; Liu *et al*., 2013; Nguyen *et al.*, 2017). Three papers did not state how they measured literacy (Firdaus *et al.*,2017; Fortes *et al*., 2011; Gupta *et al.*, 2020). One paper (Simkhada *et al.*, 2018) classed people as literate or illiterate based on self-report ability to read and write.

Table 2.1: Study characteristics

Author(s) and date	**Country**	**Study Design**	**Study aims**	**Sample/population**	**Quality rating score**
Lincoln *et al.* (2021)	USA	Cross-sectional mixed methods	Examines literacy among people seeking care in a state funded mental health clinic (Site 1) and a safety-net hospital clinic (Site 2).	• *n*= 223 • Adults aged 18 and over • Attendees of two urban, public outpatient mental health clinics	7
Nguyen *et al.* (2017)	USA	Longitudinal survey data analysis	Assess the hypothesis that literacy may be a mediator of the effect of education on depressive symptoms	• *n*=16718 • Adults aged 50 and over • Participants from the Health Retirement Study (HRS), a longitudinal study of U.S. adults aged 50 and over and their spouses.	9
Rong *et al.* (2019)	China	Cross sectional survey (face to face interviews)	Assess the status of depressive symptoms and quality of life (QoL) among rural elderly in central China (Anhui Province) and explore correlations and associated factors for depressive symptoms.	• *n*= 3349 • Adults aged 60 and over • Community dwelling in Anhui Province, China	8
Liu *et al.* (2013)	China	Cross sectional survey data and follow up face to face interviews	Examine the relationship between illiteracy and schizophrenia in Chinese sample	• *n*= 1909205 • Adults aged 18 and over • Data utilised from the 'Second China National Sample Survey on Disabilities (2006)'	9
Baral and Bhagawati (2019)	Nepal	Cross sectional	Investigate the prevalence of post-traumatic stress disorder and use of	• *n*= 291 • Adults aged 20 and over	7

		survey (face to face interviews)	coping strategies among adult survivors of Nepalese 2015 earthquake.	• Survivors of Nepal Earthquake 2015	
Manandhar *et al.* (2019)	Nepal	Cross sectional survey (face to face interviews)	Estimate the prevalence and any associated factors of depression among the elderly in the Kavre district	• *n*= 439 • Adults aged 60 and over • Community dwelling based in Kavre district, Nepal	10
Simkhada *et al.* (2018)	Nepal	Cross sectional survey (face to face interviews)	Examine the prevalence of depressive symptoms and explore possible contributory risk factors in older adults living in Nepal.	• *n*= 300 • Adults aged 60 years and over • Community dwelling based in Kathmandu, Nepal	10
Basnet *et al.* (2018)	Nepal	Cross sectional survey (face to face interviews)	Explore depression and anxiety among war-widows from the Nepalese civil war	• *n*= 358 • Female survivors of conflict who were married women and whose husband was killed or made to disappear during the civil war period (1996–2006)	6
Charoensakulchai *et al.* (2019)	Thailand	Cross sectional survey (face to face interviews)	Evaluate the prevalence and associated factors for geriatric depression	• *n*=433 • Adults aged 60 and over • Community dwelling in Ban Nayao community	9
Hassanzadeh *et al.* (2018)	Iran	Cross sectional survey data analysis	Explore the association(s) between demographic factors, smoking status, social capital, and poor mental health status in a sample of Iranian men.	• *n*= 11064 • Adults aged 20 and over • Males based in Tiran, Iran	8
Gupta *et al.* (2020)	India	Cross sectional survey (face	Estimate the prevalence of depression and the various risk factors related to it among rural adult population.	• *n*=800 • Adults aged 18 and over • Rural population based in Jammu Northwest India	9

Table 2.1: Study characteristics

		to face interviews)			
Firdaus (2017)	India	Cross sectional survey (face to face interviews)	Examine the relationship between specific components of social environment and psychological well-being of migrants in an urban centre.	• *n*= 1230 • Adults aged 18 and over • Migrant workers based in Delhi, India	8
Mathias *et al.* (2015)	India	Cross sectional survey (face to face interviews)	Describe depression prevalence, healthcare seeking and associations with socioeconomic determinants in a district in North India.	• *n*=958 • Adults aged 18 and over • Community dwelling in Dehradum district, India	9
Kohli *et al.* (2013)	India	Cross sectional survey (face to face interviews)	Describe the prevalence of unrecognised depression among outpatient attendees of a rural hospital in Delhi, India and its sociodemographic correlates.	• *n*=395 • Adults aged 18 and over • Attendees of outpatient department, Rural Delhi, India	9
Boakye-Yiadom *et al.*, (2015)	Ghana	Cross sectional survey (face to face interviews)	Assess the prevalence of stress and anxiety, as well as the association that exists between stress/anxiety and sociodemographic characteristics, among pregnant women in Ghana.	• *n*= 154 • Adults aged 18 and over • Pregnant women visiting the Tamale West hospital for antenatal care	6
Farooq *et al.* (2019)	Pakistan	Cross sectional survey (face to face interviews)	Estimate the prevalence of anxiety and depressive symptoms and their association with multimorbidity and the demographic characteristics of adults aged 30 years and above in Karachi, Pakistan.	• *n=2867* • adults aged over 30 years • Community dwelling in in the Gulshan-e-Iqbal town of Karachi, Pakistan.	9
Safi and Tariq (2013)	Pakistan	Cross sectional survey (face	Assess the prevalence of, and to identify the non-hormonal risk factors associated with depression among	• *n*=300 • Adults aged 18 years and older • Pregnant women accessing prenatal care at Hayatabad	7

Table 2.1. Study characteristics

		to face interviews)	pregnant women attending antenatal clinic in Peshawar Pakistan.	Medical Complex, (HMC) hospital Peshawar, Pakistan	
Mubeen *et al.* *(*2012)	Pakistan	Cross sectional survey (questionnaire)	Describe the prevalence of depression and to identify associated risk factors among community dwelling elderly in Karachi.	• *n*=284 • Adults aged 60 and over • Community dwelling based in Karachi, Pakistan	7
Fortes *et al.* (2011)	Brazil	Cross sectional survey (face to face interviews)	Detect if there was any group of patients within the Family Health Strategy at greater risk for common mental disorders and to recommend alternative interventions to aid those patients.	• *n*=714 • Adults aged 18 to 65 • Attendees of a family Health centre in Petropoplis, Brazil	7

Association between literacy and Mental health

Table 2.2 outlines the main outcomes relating to the relationship between literacy and mental health for each paper. Fourteen of the papers used odds ratios (OR) (Basnet *et al*., 2018; Charoensakulchai *et al*., 2019; Farooq *et al*., 2019; Firdaus *et al*.,2017; Gupta *et al*., 2020; Hassandzadeh *et al*., 2018; Kohli *et al*., 2013; Lincoln *et al.*, 2021; Liu *et al*., 2013; Manandhar *et al*., 2019; Mathias *et al*., 2015; Nguyen *et al*., 2017; Rong *et al*., 2019; Simkhada *et al*., 2018) to analyse the association between literacy and mental health. An OR represents the likelihood of an outcome occurring given a particular exposure, compared to the odds of an outcome occurring in the absence of that exposure. One paper used prevalence ratios (Fortes *et al.*, 2011) and the remaining four papers used Chi square as the main statistical outcome (Baral and Bhagawati, 2019; Boakye-Yiadom *et al*., 2015; Mubeen *et al*., 2012; Safi and Tariq, 2013).

Seventeen of the papers (Basnet *et al*., 2018; Baral and Bhagawati, 2019; Charoensakulchai *et al*., 2019; Farooq *et al*., 2019; Firdaus, 2017; Fortes *et al.*,2011; Gupta *et al*., 2020; Hassandzadeh *et al.*,2018; Kohli *et al*., 2013; Liu *et al*., 2013; Manandhar *et al*., 2019; Mathias *et al*., 2015; Mubeen *et al.*,2012; Nguyen *et al.*,2017; Rong *et al*., 2019; Safi and Tariq, 2013) (90%) found a statistically significant association between poorer literacy and poorer mental health outcomes. One paper found no significant association (Lincoln *et al.*,2021). One paper reported that higher literacy was significantly associated with poorer mental health outcomes (Boakye-Yiadom *et al.*, 2015). However, when doing post hoc calculations using the available raw data presented in the publication, the authors of this systematic review failed to replicate this finding.

Table 2.2: Study outcomes

Author (s) and date	**Literacy measure (s)**	**Mental health measure(s) (mental health condition assessed)**	**Main results relating to literacy and mental health**	**Factors found to be partial mediators of relationship between literacy and mental health outcomes**	**Demonstrated a significant association between literacy and mental health**
Lincoln *et al.* (2021)	Woodcock-Johnson III test of achievement (WJ) used to categorise literacy abilities	Diagnostic data (ICD-9 codes) from patients' medical records (depression, anxiety, PTSD, bipolar disorder, and schizophrenia-spectrum disorders)	Whilst some relationships between literacy and mental health diagnoses were found when models were adjusted to include neurocognitive and sociodemographic characteristics these associations were no longer significant		No
Nguyen *et al.* (2017)	Brief vocabulary test and years of schooling	Center for Epidemiologic Studies Depression, CES-D (Depression)	Descriptive statistics showed that people with the combination of poor literacy and lower education attainment had higher depression scores Literacy was found to be a statistically significant partial mediator of the relationship between education and depressive symptoms, accounting for 28% of the effect.	• Years of schooling	Yes
Rong *et al.* (2019)	Categorised by educational status,	Geriatric Depression Scale, GDS 30 (Depression)	Illiteracy was a statistically significant associated factor for depressive symptoms among rural elderly persons OR 1.34 (1.125-1.595) p=0.001		Yes

Table 2.2. Study outcomes

	including illiterate				
Liu *et al.* (2013)	Chinese character recognition test, if reported no schooling interviewer would ask further questions	International Classification of Diseases, ICD-10, symptom checklist (Schizophrenia)	Illiteracy was significantly associated with schizophrenia Adjusted OR 2.08 (1.84-2.36) Young illiterates showed a high prevalence of schizophrenia PR 7.54 (6.20-9.18)	• Age	Yes
Baral and Bhagawati (2019)	Classified as literate or illiterate and educational status	PTSD symptom checklist, PCL-5. (Post-traumatic Stress disorder, PTSD)	Significantly more illiterates (25.5%) had PTSD compared to literates (13.9%) p<0.0001		Yes
Manandhar *et al.* (2019)	Dichotomised educational status as illiterate or literate	Geriatric Depression Scale, GDS 15 (Depression)	Illiteracy was significantly associated with geriatric depression OR 3.1 (1.7–5.1) p<0.001 Adjusted OR 2.1 (1.1-4.0) p=0.037		Yes
Simkhada *et al.* (2018)	Classified as illiterate or literate (able to read and write)	Geriatric Depression Scale, GDS 15 (Depression)	Illiteracy was significantly associated with twice the likelihood of having depression Adjusted OR 2.01 (1.08–3.75)		Yes
Basnet *et al.* (2018)	Classified educational status as illiterate or literate	Beck's Depression Inventory-21, BDI-21 (Depression) Beck's Anxiety Inventory-21, BAI-21 (Anxiety)	Illiteracy was significantly associated with moderate anxiety and depression. Being literate significantly reduced the odds of moderate severity depression score, OR 0.49 (0.26–0.91)		Yes

Table 2.2 Study outcomes

			Being literate significantly reduced the odds of moderate severity anxiety score, OR 0.23 (0.12–0.43)		
Charoensakulchai *et al.* (2019)	Categorised as illiterate or at least primary education	Thai version of the Geriatric Depression Scale, TGDS (Depression)	Illiteracy was significantly associated with risk for depression Adjusted OR 2.86, (1.19–6.17) p= 0.04		Yes
Hassanzadeh *et al.* (2018)	Categorised by educational status, including illiterate category	General Health Questionnaire 28, GHQ-28 (Mental health status)	Illiteracy was directly associated with poor mental health status Adjusted OR 1.18 (1.09-1.29) p=0.04		Yes
Gupta *et al.* (2020)	Classified educational status as illiterate or literate	Patient Health Questionnaire, PHQ-9 and Beck's Depression Inventory, BDI-II (Depression)	Illiteracy was significantly associated with depression OR 3.8 (1.31-11.06) p<0.001		Yes
Firdaus (2017)	Unclear how obtained literacy status but Illiterate as a respondent characteristic	World Health Organization Well-Being Index, WHO5 (Mental wellbeing)	Illiteracy was significantly associated with poor mental well-being OR = 2.55 (1.91-2.43 p< 0.01)	• Year of immigration • Living condition	Yes
Mathias *et al.* (2015)	Categorised by educational status, unschooled classed as illiterate	Patient Health Questionnaire- 9, PHQ-9 (Depression)	Illiteracy (or being unschooled) was a significant risk factor for depression. People who had not completed primary schooling had almost four times greater risk of depression after controlling for other variables		Yes

Table 2.2 Study outcomes

			Adjusted OR 3.7 (1.2-12.0)		
Kohli *et al.* (2013)	Categorised by educational status, including illiterate category	Primary Care Evaluation of Mental Disorders, PRIME MD Patient Health Questionnaire-9, PHQ-9 (Depression)	Education status (illiteracy) was significantly associated with presence of depression ($\chi 2= 14.3$, df=6 and p=0.026) When only looking at those that had no previous diagnosis, literacy was associated with less odds of having depression OR=0.54, (0.328-0.911) p=0.02		Yes
Boakye-Yiadom *et al.*, (2015)	Categorised by educational status, including illiterate category	Kessler Psychological Distress Scale, K10 (Stress) State Trait Anxiety Inventory STAI (Anxiety)	There was no statistically significant association between illiteracy and stress. However, a higher proportion of people who had attained tertiary educational status had anxiety disorders (p=0.0421)		Negative impact of literacy
Farooq *et al.* (2019)	Categorised by educational status	Aga Khan University Anxiety Depression Scale, AKUADS (Depression, Anxiety)	Illiteracy (defined as no formal education vs higher education) was a significant factor associated with anxiety and depression symptoms Adjusted OR 1.51 (1.09 to 2.07)		Yes
Safi and Tariq (2013)	Categorised by educational status, uneducated= illiteracy	Centre for Epidemiologic Studies Depression Scale, CES-D (Depression)	Statistically more women who were uneducated/illiterate (90%) had depression compared to those who were educated (81%) p value = 0.00		Yes
Mubeen *et al.* *(*2012)	Categorised by educational status, including	Geriatric Depression Scale, GDS 15 (Depression)	Illiterates had significantly higher levels of depression (P<0.001)		Yes

Table 2.2 Study outcomes

	illiterate category				
Fortes *et al.* (2011)	Categorised by educational status, including illiterate category	General Health Questionnaire, GHQ-12 (Common mental disorders, CMD)	No statistically significant association between illiteracy and common mental disorders. Adjusted PR 1.06 (0.84-1.40) However, illiterate patients who were not extremely poor presented an increase of 8.5% in CMD compared to illiterates who were extremely poor. Crude PR 1.38 (1.07-1.78) P=0.042	• Gender • Monthly income	No overall effect but effect when looking at poverty level as mediator

Four papers explored mediating factors in the association between literacy and mental health. Liu *et al. (*2012) reported that age mediated the relationship between literacy and schizophrenia, with the strongest association amongst those under 40 years old and the greatest prevalence in the 18–19-year-old cohort (OR=1.64 % , 95 % CI: 1.35, 1.93). Firdaus *et al.* (2017) reported that amongst an immigrant population, the year of immigration and poor housing conditions combined with low levels of education (used as a proxy for literacy) were associated with poorer mental health outcomes. Fortes *et al.* (2011) reported that low literacy in females in all but those who were extremely poor, presented an increase of 8.5% in CMD. Nguyen *et al.* (2017) found that literacy itself was an independent variable of the relationship between years of education and depressive symptoms. Specifically, literacy mediated the relationship between education and depressive symptoms, predominantly among those with lower levels of education. Literacy was found to be a statistically significant partial mediator of the relationship between education and depressive symptoms, accounting for 28% of the effect.

Discussion

This review identified 19 studies that looked at the relationship between mental health outcomes and literacy. Most studies (68%) examined depression levels as the mental health outcome. The review included papers from nine countries. The majority of papers (90%) indicated a significant association between literacy abilities and mental health outcomes, with poorer literacy abilities associated with poorer mental health outcomes. Whilst causality cannot be argued as most studies were cross-sectional, it suggest there is an association between literacy and mental health outcomes across multiple countries.

Some papers examined related variables that might interact with the relationship between literacy and mental health. Age, gender, years of schooling, and poverty level were all found to have interaction effects with the relationship between literacy and mental health. It is difficult to summarise generalisable conclusions about these interactions as the review is limited by what the papers included in their analyses. Not all papers looked at interactions between variables, thus there is limited information on these more complex associations and further research is needed to understand these relationships. However, given these factors all represent social inequalities, the findings contribute to our understanding of the social determinants of mental health. Allen *et al.*,(2014) conclude that mental health is shaped by the social, economic, and physical environments in which we live, and they recognise that social inequalities act as risk factors for mental health, with poorer people disproportionately impacted.

There are several ways in which literacy and mental health may impact on each other. From a socio-economic perspective, poor literacy skills may limit opportunities for engaging with society (Cree, Kay, and Steward 2012) as well as limiting access to well paid jobs (Dugdale and Clark, 2008) and thus socio-economic status and financial security. Literacy skills have been found to impact on an individual’s psychological empowerment, feelings of self-esteem and- self-confidence (Stromquist, 2009). Research also suggests that literacy impacts on help seeking and health care utilisation (Baker *et al.*, 1996). Further to this, the intersectionality of literacy and mental health difficulties (Lincoln *et al.*, 2017) may also be a contributing factor to this relationship. Easton *et al.* (2013) identify that the stigma associated with poor literacy may contribute to poorer mental health. The current review supports the notion of poor literacy being a social inequality which contributes to poorer outcomes for individuals, including poorer mental health. However, it is essential for future research to explore the relationship between literacy and mental health further, as well as the mechanisms behind this relationship

Within the included papers educational status was often used as a proxy measure for literacy abilities. Using educational attainment, or years of schooling, as a measurement of literacy assumes those who attend school gain literacy skills, and those that don't access education do not have literacy skills. However, research has shown that literacy and education are related but separate constructs (UNICEF, 2015), thus educational attainment is unlikely to be a true reflection of literacy abilities. Research also shows that education itself has a positive impact on both health (Cutler and Lleras-Muney's, 2006) and mental health (Chevalier and Feinstein, 2006) outcomes. Whilst literacy and education are related, the research available suggests that using educational attainment as a measure of literacy may present a misleading picture. For a true reflection of the relationship between literacy and mental health, a literacy measure should be developed and utilised.

It is important to consider the different contextual factors within the countries included in this review. Given that education was often used as a proxy for literacy, the variety of access to and standard of education across the countries should be considered. Mean years of schooling for the countries included in the review ranged from 5 to 13 years (Baumann, 2021). Whilst this shows variety in amount of education access, education in different countries may also vary based on sex, health, cultural identity, and poverty. The availability of mental health services across the different countries should also be considered. Despite mental health being the leading cause of disability worldwide (Mensah and Collins, 2015), there is a significant mental health treatment gap, particularly in low and middle income countries, where 75% of people who need mental health services lack access to the appropriate care and support (Kohn *et al.*, 2004). Interestingly this is where the majority of the included papers originated from.

Implications

Whilst this systematic review can not ascertain direction of the relationship between literacy abilities and mental health outcomes it does suggests an association between the two. If we were to hypothesise that poorer literacy leads to poorer mental health outcomes a focus on promoting literacy from an early age, and across the lifespan, has the potential to have a positive impact on mental health outcomes. Future research could look to explore the direction of this relationship using a literacy intervention and measuring the impact on mental health outcomes. Irrespective of the direction of the relationship between literacy and mental health, it also highlights the importance of healthcare professionals being able to identify and support people with literacy difficulties within mental health practice settings.

Limitations

This systematic review aimed to give a global picture of the association between literacy and mental health. However, the studies included in this review only covered nine countries, most of which were low- and middle-income countries, therefore, it cannot be considered truly representative of the global picture. Whilst it does give us an insight into the picture across multiple countries, it would be useful to have research looking at the association between literacy and mental health across a wider range of countries. Perhaps the lack of research in high income countries looking at the association between literacy and mental health reflects an assumption of literacy in these countries. Consideration should also be given to the cross-cultural differences in the perceptions, experience, and reporting of mental health difficulties within the different countries included in this review. For example, whilst all the measures of mental health were validated measures they are frequently constructed with a westernised understanding and conceptualisation of mental health.

The quality of the papers included in this review was mixed; less than half of the papers were categorised as good quality. Due to the high level of fair to low quality papers it is difficult to draw strong and valid conclusions. This highlights the need for further methodologically sound research looking at the association between mental health and literacy.

Due to the range of methods used to assess literacy abilities and mental health outcomes a meta-analysis was not able to be completed with the included studies, so the data were unable to be combined for statistical analysis. Furthermore, it is recognised that many of the included studies use years of education as a proxy measure for literacy abilities and thus may not most accurately capture true literacy abilities.

Conclusion

Based on a limited number of papers, this systematic review suggests there is a relationship between literacy and mental health outcomes, with poorer literacy being associated with poorer mental health outcomes. However, there is a limited evidence base from a small proportion of countries and further research that directly assesses literacy abilities and mental health is needed.. This review also highlights the need for mental health clinicians to be able to identify and support those with literacy needs within mental health services.

References

Allen, J., Balfour, R., Bell, R. and Marmot, M. (2014), “Social determinants of mental health”, *International review of psychiatry*, Vol. 26 No. 4, pp.392-407.

Arnold, E.M., Goldston, D.B., Walsh, A.K., Reboussin, B.A., Daniel, S.S., Hickman, E. and Wood, F.B. (2005), “Severity of emotional and behavioral problems among poor and typical readers”. *Journal of abnormal child psychology,* Vol. 33 No. 2, pp.205-217.

Baker, D.W., Parker, R.M., Williams, M.V., Pitkin, K., Parikh, N.S., Coates, W. and Imara, M. (1996), “The health care experience of patients with low literacy”, *Archives of family medicine*, Vol. 5 No. 6, p.329.

Baker, D.W., Gazmararian, J.A., Williams, M.V., Scott, T., Parker, R.M., Green, D., Ren, J. and Peel, J. (2002), “Functional health literacy and the risk of hospital admission among Medicare managed care enrollees.” *American journal of public health*, Vol. 92 No.8, pp.1278-1283.

Baral, I.A. and Bhagawati, K.C. (2019), "Post traumatic stress disorder and coping strategies among adult survivors of earthquake, Nepal", *BMC psychiatry,* Vol. 19 No. 1, pp.1-8.

Basnet, S., Kandel, P. and Lamichhane, P. (2018), “Depression and anxiety among war-widows of Nepal: a post-civil war cross-sectional study”, *Psychology, Health and Medicine*, Vol. 23 No.2, pp.141–153.

Baumann, F. (2021), “The Next Frontier—Human Development and the Anthropocene: UNDP Human Development Report 2020.” *Environment: Science and Policy for Sustainable Development,* Vol. 63 No. 3, pp.34-40.

Berkman, N.D., DeWalt, D.A., Pignone, M.P., Sheridan, S.L., Lohr, K.N., Lux, L., Sutton, S.F., Swinson, T. and Bonito, A.J. (2004), “Literacy and health outcomes: summary.” *AHRQ evidence report summaries.*

Boakye-Yiadom, A., Shittu, S.O., Dutt, J.B., Dapare, P.P.M. and Alhassan, A. (2015), “Perceived stress and anxiety among Ghanaian pregnant women”, *Journal of Medical and Biomedical Sciences*, Vol. 4 No. 2, pp.29-37.

Boyes, M. E., Leitao, S., Claessen, M., Badcock, N. A., and Nayton, M. (2016), “Why are reading difficulties associated with mental health problems?.” *Dyslexia*, Vol. 22 No. 3, pp.263-266.

Charoensakulchai, S., Usawachoke, S., Kongbangpor, W., Thanavirun, P., Mitsiriswat, A., Pinijnai, O., Kaensingh, S., Chaiyakham, N., Chamnanmont, C., Ninnakala, N. and Hiri-o-Tappa, P. (2019), "Prevalence and associated factors influencing depression in older adults living in rural Thailand: a cross-sectional study", *Geriatrics and gerontology international,* Vol. 19 No. 12, pp.1248-1253.

Chevalier, A., and Feinstein, L. (2006), “Sheepskin or Prozac: The causal effect of education on mental health.” *IZA Discussion Paper 2231*.

Cree, A., Kay, A. and Steward, J. (2012), "The economic and social cost of illiteracy: A snapshot of illiteracy in a global context", *World Literacy Foundation.*

Critical Appraisal Skills Programme (2018), “CASP Cohort Study Checklist.” Available at: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Cohort-Study-Checklist_2018.pdf (accessed 20 Sept 2021)

Cutler, D. M., and Lleras-Muney, A. (2006), “Education and health: evaluating theories and evidence.” NBER Working Paper No. 12352.

Desa, U. N. (2016), "Transforming our world: The 2030 agenda for sustainable development."

DeWalt, D.A., Berkman, N.D., Sheridan, S., Lohr, K.N. and Pignone, M.P. (2004), "Literacy and health outcomes", *Journal of general internal medicine,* Vol. 19 No. 12, pp.1228-1239.

Downes, M.J., Brennan, M.L., Williams, H.C. and Dean, R.S. (2016), “Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS).” *BMJ open,* Vol. 6 No.12

Dugdale, G. and Clark, C. (2008), “Literacy changes lives : An advocacy resource”, *National Literacy Trust.*

Easton, P., Entwistle, V.A. and Williams, B. (2013), “How the stigma of low literacy can impair patient-professional spoken interactions and affect health: insights from a qualitative investigation.” *BMC health services research,* Vol. 13 No. 1, pp.1-12.

Farooq, S., Khan, T., Zaheer, S. and Shafique, K. (2019), “Prevalence of anxiety and depressive symptoms and their association with multimorbidity and demographic factors: a community-based, cross-sectional survey in Karachi, Pakistan”, *BMJ open,* Vol. 9 No. 11, p.e029315.

Firdaus, G. (2017), “Mental well-being of migrants in urban center of India: Analyzing the role of social environment.” *Indian journal of psychiatry,* Vol 59 No. 2, pp.164.

Fortes, S., Lopes, C.S., Villano, L.A., Campos, M.R., Gonçalves, D.A. and Mari, J.D.J. (2011), “Common mental disorders in Petrópolis-RJ: a challenge to integrate mental health into primary care strategies”, *Revista Brasileira de Psiquiatria,* Vol. 33 No. 2, pp.150–156.

Francis, D. A., Caruana, N., Hudson, J. L., and McArthur, G. M. (2019), "The association between poor reading and internalising problems: a systematic review and meta-analysis." *Clinical Psychology Review*, Vol. 67, pp.45-60.

Gilbert, L., Teravainen, A., Clark, C. and Shaw. (2018), "Literacy and life expectancy and socioeconomic factors", *National Literacy Trust,* (1116260).

Gupta, C., Arora, M., Gupta, R.K., Akhtar, N., Langer, B., Kumari, R., Sharma, P., Majeed, M. and Raina, S.K. (2020), "Prevalence and correlates of depression in a rural adult population in Northwest India." *Journal of Family Medicine and Primary Care,* Vol 9 No 1, p.151.

Hassanzadeh, J., Asadi-Lari, M., Ghaem, H., Kassani, A., Niazi, M. and Menati, R. (2018), "The Association of Poor Mental Health Status and Sociocultural Factors in Men: A Population-Based Study in Tehran, Iran", *American Journal of Men's Health,* Vol. 12 No. 1, pp.96–103.

Kohli, C., Kishore, J., Agarwal, P. and Singh, S.V. (2013), "Prevalence of unrecognised depression among outpatient department attendees of a rural hospital in Delhi, India", *Journal of Clinical and Diagnostic Research,* Vol. 7 No. 9, pp.1921–1925.

Kohn, R., Saxena, S., Levav, I. and Saraceno, B. (2004), "The treatment gap in mental health care", *Bulletin of the World Health Organization*, Vol. 82 No. 11, pp.858–866.

Lincoln, A.K., Adams, W., Eyllon, M., Garverich, S., Prener, C.G., Griffith, J., Paasche-Orlow, M.K. and Hopper, K. (2017), "The Double Stigma of Limited Literacy and Mental Illness: Examining Barriers to Recovery and Participation among Public Mental Health Service Users", *Society and Mental Health*, Vol. 7 No. 3, pp.121–141.

Lincoln, A.K., Eyllon, M., Prener, C., Garverich, S., Griffith, J., Adams, W., Arford, T., Rosenfeld, L., Nykiel, S., Johnson, P. and Guyer, M. (2021), “Prevalence and Predictors Limited Literacy in Public Mental Health Care”, *Community Mental Health Journal. Springer US,* Vol. 57 No. 6, pp.1175–1186.

Liu, T., Song, X., Chen, G., Buka, S.L., Zhang, L., Pang, L. and Zheng, X. (2013), “Illiteracy and schizophrenia in China: A population-based survey”, *Social Psychiatry and Psychiatric Epidemiology,* Vol. 48 No.3, pp.455–464.

Manandhar, K., Risal, A., Shrestha, O., Manandhar, N., Kunwar, D., Koju, R. and Holen, A. (2019), “Prevalence of geriatric depression in the Kavre district, Nepal: Findings from a cross sectional community survey”, *BMC Psychiatry,* Vol. 19 No. 1, pp.1-9.

Mathias, K., Goicolea, I., Kermode, M., Singh, L., Shidhaye, R. and San Sebastian, M. (2015), “Cross-sectional study of depression and help-seeking in Uttarakhand, North India”, *BMJ Open*, Vol. 5 No. 11, pp.1–8.

Mensah, G.A. and Collins, P.Y. (2015), “Understanding mental health for the prevention and control of cardiovascular diseases.” *Global heart,* Vol. 10 No. 3, p.221.

Morgan, P.L., Farkas, G. and Wu, Q. (2012), “Do poor readers feel angry, sad, and unpopular?.” *Scientific Studies of Reading,* Vol. 16 No. 4, pp.360-381.

Morrisroe, J. (2014), “Literacy Changes Lives. A new perspective on health, employment and crime”, *National Literacy Trust*, pp.1–26.

Mubeen S. M., Henry, D. and Qureshi, S. N. (2012), “Prevalence of depression among community dwelling elderly in Karachi, Pakistan”, *Iranian Journal of Psychiatry and Behavioral Sciences,* Vol. 6 No. 2, pp.84–90.

Murray, J. (2021), “Literacy is inadequate: young children need literacies.*” International Journal of Early Years Education*, Vol. 29 No. 1, pp.1-5.

Nguyen, T.T., Tchetgen, E.J.T., Kawachi, I., Gilman, S.E., Walter, S. and Glymour, M.M. (2017), “The role of literacy in the association between educational attainment and depressive symptoms”, *SSM - Population Health. Elsevier*, Vol. 3, pp.586–593.

Rong, J., Chen, G., Wang, X., Ge, Y., Meng, N., Xie, T. and Ding, H. (2019), “Correlation between depressive symptoms and quality of life, and associated factors for depressive symptoms among rural elderly in Anhui, China”, *Clinical Interventions in Aging*, Vol. 14, pp.1901–1910.

Roser, M. and Ortiz-Ospina, E. (2016), “Literacy” *Our World in Data.* https://ourworldindata.org/literacy.

Safi, F.N. and Tariq, H. (2013), “Antenatal depression: Prevalence and risk factors for depression among pregnant women in Peshawar.” *Journal of Medical Sciences*, Vol 21 No 4, pp.206-211.

Sentell, T. L., and Shumway, M. A. (2003), “Low literacy and mental illness in a nationally representative sample.” *The Journal of nervous and mental disease*, Vol. 191 No. 8, pp.549-552.

Simkhada, R., Wasti, S.P., Gc, V.S. and Lee, A.C. (2018), “Prevalence of depressive symptoms and its associated factors in older adults: a cross-sectional study in Kathmandu, Nepal”, *Aging and Mental Healt*h, Vol. 22 No. 6, pp.802–807.

Snowling, M.J., Muter, V. and Carroll, J. (2007), “Children at family risk of dyslexia: a follow-up in early adolescence.” *Journal of child psychology and psychiatry*, Vol. 48 No.6, pp.609-618.

Stromquist, N. P. (2009), “Literacy and Empowerment: a contribution to the debate”, *United Nations Literacy Decade - UNESCO,* pp.1–13.

U.N Department of Economic and Social Affairs. (2016), *Transforming our world: The 2030 agenda for sustainable development,* New York.

UNESCO. (2017), *Literacy Rates Continue to Rise from One Generation to the Next Fact Sheet,* UNESCO institute for statistics, Fact sheet 45.

UNESCO. (2019), *Global Education Monitoring Report–Gender Report: Building bridges for gender equality,* UNESCO, Paris.

UNESCO. (2021), UNESCO Institute for Statistics. Literacy. http://uis.unesco.org/en/topic/literacy.

UNICEF. (2015), *The Investment Case for Education and Equity*, UNICEF, New York.

Wells, G. A., Shea, B., O’Connell, D., Peterson, J., Welch, V., Losos, M., and Tugwell, P. (2000), “The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses.”

Wolf, M. and Stoodley, C. J. (2008), *Proust and the squid: The story and science of the reading brain*, Harper Perennial, New York.

Zhang, Q. (2021), “The cost of illiteracy: A causal inference study on how illiteracy affects physical and mental health”, *Health Education Journal,* Vol. 80 No. 1, pp.54–66.

Zua, B. (2021), “Literacy: Gateway to a World of Exploits.”, *International Journal of Education and Literacy Studies*, Vol. 9 No 1, pp.96-104.

Chapter Three

Bridging Chapter

Bridging chapter

This bridging chapter provides a brief summary of the findings in the systematic review and explains the rationale and background for the empirical project.

The systematic review in this portfolio suggests that there is a relationship between literacy abilities and mental health outcomes when measured across a range of countries and cultural contexts. The review found that poorer literacy abilities were associated with poorer mental health outcomes. Whilst the systematic review was able to describe a quantitative or measurable association between literacy and mental health, a causal relationship cannot be established due to the cross-sectional nature of the majority of the studies included. Whilst cross-sectional research is essential for developing our knowledge of prevalence (Kesmodel, 2018) and can indicate what happens to different demographic groupings, it is unable to explore the complex interplay of factors that impact on an individuals' experiences (Rich and Ginsburg, 1999). Qualitative research can complement cross-sectional research by providing us with an in-depth exploration of individuals' experiences and impacts of phenomena, which is important when trying to inform context-specific changes in organisational practice and culture. Thus, the empirical research project draws on qualitative research methods to explore the complex layers of experience for those with literacy difficulties and mental health difficulties, from the perspective of mental healthcare professionals who have supported people with literacy difficulties in mental health services.

Further to this, the narrative synthesis in the systematic review highlighted some associated factors that were reported to mediate the relationship between literacy and mental health in a few select studies. Age, gender, years of education, and poverty level were all found to play a role in the relationship between literacy and mental health outcomes. Given that all of these mediating factors represent social inequalities (The Kings Fund, 2020), this finding adds to our understanding of literacy as a potential social determinant of mental health and has significant clinical implications. Given this commonality between literacy and mental health as a social determinant it would be helpful to explore how stigma, a major determinant of health (Goldberg, 2017), might play a role in the mechanisms that link these two concepts.

Compton and Shim (2015) recognise part of the role of clinicians is to screen for and address the effects of social determinants of mental health through both individual level interventions and advocating for changes to policy and social norms. Compton et al. argue that mental healthcare professionals have a role in addressing discrimination and social exclusion in public and policy discourse. Thus, the empirical research project drew on qualitative methods to understand how this association between literacy and mental health is experienced within the mental health practice context of the NHS, and the influencing societal factors. Qualitative methods are appropriate to cultivate a richness of data that could explore the organisational, cultural, and structural factors at play when supporting people with literacy difficulties in these practice settings (Tuckerman et al., 2020). This allows the identification of organisation specific improvements that may be able to help address this potential social determinant of mental health.

The empirical research project aimed to address some of the gaps in the existing literature around clinicians’ perceptions and experiences of how best to support people with literacy difficulties within UK health services. The NHS Long Term Plan (2019) identifies a key aim of the NHS is to continue to shift toward a more person-centred care approach, empowering individuals to have more control over their care and a sense of joint responsibility. The long-term plan recognises the need for professionals to work differently, in order to create genuine partnership with those they care for. It also identifies that a systematic approach to engaging patients in decisions about their health and wellbeing is essential. This will require supporting and training staff to have conversations which enable individuals to make decisions that are right for them. The WHO (2014) also identifies that at the heart of addressing social determinants of mental health is empowerment of individuals and communities. Given this recent shift in strategy within the NHS, and wider recognition of the need for empowerment to address inequalities, the empirical research project was specifically interested in mental health clinicians’ experience of delivering person-centred care with those who have literacy needs.

Chapter Four

Empirical Paper

Empirical paper prepared for submission to ‘Society and Mental Health’ Journal.

Author guidelines can be found in Appendix E

Clinician Insights into the Impact of Literacy Difficulties on Person-centred Care within Mental Health Services

Lucy Hunn*- University of East Anglia

Bonnie Teague- University of East Anglia

Total Word count:6474

Number of tables:1

Number of figures:0

*Corresponding author (Lucy Hunn: Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ, l.hunn@uea.ac.uk)

Clinician Insights into the Impact of Literacy Difficulties on Person-centred Care within Mental Health Services

Abstract

Prior research suggests an association between low literacy and poorer mental health outcomes, mediated in part by wider social determinants and stigma. Given that stigma can impact on an individual's relationship with healthcare professionals, it is important to understand healthcare professionals' perceptions, understanding, and beliefs around literacy within the clinical environment. This co-produced study interviewed mental health clinicians with experience of working with individuals with low literacy. Thematic analysis found five overarching themes which reflect participants views on how the intersectionality of literacy and mental health difficulties creates a global impact on someone's life, with societal stigmas creating an inequality for these individuals. Participants discussed how they felt services are often inaccessible for those with low literacy and thus can potentially further reinforce this stigma. Participants also expressed emotive responses and a passion for advocating for those with literacy needs, using a humanistic approach to support individuals through their journey with mental health services.

Clinician Insights into the Impact of Literacy Difficulties on Person-centred Care within Mental Health Services

Introduction

Literacy, one’s ability to read, write, speak, and listen (Jacobs, 2014), has a vast impact on an individual’s experiences of the world and their ability to engage in society. The National Literacy Trust (NLT) reports that 16.4% of adults in England can be described as having ‘very poor literacy skills’ (Literacy Trust, 2012). Previous research has shown a relationship between literacy abilities and mental health. Francis et al. (2019) found that poorer readers had an increased risk of anxiety and depression across the lifespan. Within younger populations, reading difficulties have been found to have associations with internalising difficulties such as depression (Arnold et al. 2005; Eissa 2010; Whitehouse et al. 2009); as well as externalising difficulties such as behavioural problems (Morgan, Farka, and Wu 2012; Snowling, Mutler, and Carroll 2007). Boyes at el. (2016) provide a conceptual framework to explain the variability in the relationship between reading difficulties and mental health. This framework indicates that risk or resilience promoting factors in a child may exacerbate or ameliorate the relationship between their mental health and their reading abilities. Beyond reading skills, lower literacy in general has also been associated with poorer mental health outcomes in both working-age adults (Sentell and Shumway 2003) and older adults (Zhang 2021).

Given that there appears to be an association between poorer literacy and poorer mental health outcomes, understanding how literacy abilities might impact on someone’s interactions with mental health systems and healthcare professionals is of particular importance. Vijayalakshmi et al. (2013) suggest that literacy difficulties act as a barrier to accessing and effectively using mental health services. Despite literacy difficulties often having a significant impact on someone’s daily functioning and wellbeing, their literacy needs may still go unrecognised by healthcare professionals (Easton, Entwistle, and Williams 2013). Obvious language impairments or associated cognitive difficulties may make it clear to clinicians when someone has additional literacy needs, however there are several factors that may lead professionals to overlook someone's literacy challenges. For example, some individuals may not self-identify as having literacy difficulties (Bynner and Parsons 2006), whilst others may experience shame and stigma associated with literacy difficulties (Wolf et al. 2007), and actively try to conceal their difficulties from healthcare professionals (Parikh et al. 1996). Further to this, lack of awareness in healthcare professionals of potential literacy needs in the absence of obvious language or cognitive impairments (Bass et al. 2002) may continue to maintain this population being unidentified.

Literacy, health, and the role of stigma

Some of the maintaining factors for overlooking an individual's literacy difficulties within mental health services may be understood using stigma theory and research, given the double layer of stigma that those with literacy and mental health difficulties may experience (Lincoln et al. 2017). Herek (2009a) defines stigma as the "negative regard, inferior status, and relative powerlessness that society collectively accords to people who possess a particular characteristic or belong to a particular group or category". This social constructionist view of stigma shifts the source of stigma away from the individual and reflects its development in society. Enacted stigma such as structural inequalities, stereotypes, prejudice, and discrimination continue to maintain feelings of marginalisation due to limiting a stigmatised individual's participation in society (Frost 2011). Whilst the stigma of literacy and mental health difficulties may be generated at a societal level, it is likely that living in a society of social or enacted stigma leads individuals to internalise these negative meanings (Corrigan and Rao 2012; Vogel et al. 2013). Stigma theory postulates that stigmatised individuals regularly manage their stigmatised identity or characteristic in relation to whether they make it known to others or conceal it (Pachankis 2007). The literature describes how stigmatised individuals often adopt a range of techniques to manage their stigmatised identity (Jenkins and Carpenter-Song 2008; Meisenbach 2010). The chronic stress of stigma management has consistently been associated with poorer mental health (Frost 2011), lack of help seeking behaviour (Corrigan, Druss, and Perlick 2014), and poor communication (Meisenbach 2010).

This complex stigma experienced by those with both literacy and mental health difficulties can impact on communication and relationship-building with professionals (Lincoln et al. 2017). Individuals with low literacy have reported that they may limit their interactions with healthcare professionals and attempt to conceal misunderstandings (Easton et al. 2013). Further to this, healthcare staff report that they do not routinely screen for literacy difficulties, due to low confidence and concerns that this could be stigmatising for patients (Brooks et al. 2018). In addition to these factors, how discriminatory services are perceived to be by individuals can lead to internalisation of negative beliefs and consequently lead to service users experiencing disempowerment (Wang et al. 2018).

The impact of stigma on communication with healthcare professionals is of importance given that better service user-professional communication aids person-centred care and is linked to increased client satisfaction, adherence to medication and treatment regimes, and improved clinical outcomes (Cooper 2008; Tongue et al. 2005). Therefore, if stigma results in poor communication where individuals feel unable to be open about their literacy difficulties and clinicians aren’t asking about them, this could result in passive, disempowered service users with unmet needs (Patel and Dowse 2015) and, ultimately, poorer quality of life and recovery (Chan and Mak 2014; Roth and Crane-Ross 2002). Whilst there are likely to be multiple mechanisms that operate in the association between literacy and mental health, this project focuses on the role of stigma given it is one of the major determinants of health (Goldberg 2017) and the commonality between literacy and mental health appears to be social determinants (Schillinger 2020).

The role of person-centred care

Empowerment in healthcare is achieved at a contextual level if individuals have a sense of power or agency as a result of access to resources and options for decision making (Lee 2001). One way in which individuals can be empowered and unmet needs can be addressed is through a person-centred care approach (Gask and Coventry 2012). Communication is a key element of this (Bensing et al. 2000; Epstein et al. 2010). Health Education England recommends that as a workforce the NHS needs to support and drive person-centred approaches to wellbeing, prevention, care, and support. The NHS Long Term Plan (2019) recognises the need for a shift towards more personalised care models across the country within health services. Epstein et al. (2005) suggested three values of person-centred care: (1) considering the individual’s needs, wants, perspectives, and experiences; (2) offering individuals opportunities to provide input into and participate in their care; and (3) enhancing partnership and understanding in the service user-professional relationship. With these values in mind, Epstein et al. suggested person-centred communication should include: (A) eliciting and understanding the individual’s perspective; (B) understanding the individual within their unique psychosocial context; (C) reaching a shared understanding of the problem and its treatment with the individual that is concordant with their values; and (D) helping service users to share power and responsibility by involving them in choices to the degree that they wish.

Given the significant amount of health policy that states the need for person-centred care, it is important to explore how unrecognised literacy difficulties may impact on this interaction. The current study aims to draw on existing knowledge from research in broader areas to understand more about what might be experienced by service users and professionals within mental health settings, where several layers of stigma may be at play due to the complex interaction between mental health and literacy difficulties. Exploring how person-centred care is achieved for this population will help to deepen our understanding of how this combination of difficulties, and the known attached social stigma, may play out within someone's journey through mental health services. The current study aimed to explore experiences and perceptions of practicing clinicians and identify potential barriers or aiders in facilitating person-centred care to empower individuals who have both mental health and literacy difficulties.

Method

Qualitative methods were used to explore the research questions in this study through semi-structured interviews with mental health care professionals. A social constructionist stance has been taken given the relevance of the development of co-constructed understandings of the world that create shared assumptions about reality to this study. Using qualitative methods within a social constructionist framework aimed to explore individuals' interpretations and understandings, recognising the complexities of human nature, whilst acknowledging that meanings are formed through interactions with others.

Co-production

Based on principles by Realpe and Wallace (2010) this study was co-produced with the Green Light Champion Network (GLCN) within the mental health care organisation. The GLCN is a collection of volunteers made up of clinicians, service users, and third-party representatives. This network of people aims to drive quality improvements around the accessibility of services across the trust and within associated services. The GLCN requested further research to explore how clinicians working within the mental healthcare organisation, were addressing the needs of those with literacy difficulties. Therefore, the research priorities and questions originated from the co-production group and they were directly involved throughout the different stages of the research project. The overall network acted as a wider co-production group, the composition of this group was dynamic and those that attended each meeting differed and thus potentially different people contributed at different points of the study. In addition, there was a smaller co-production working group who met regularly to discuss the finer details of the research. Initially this working group was comprised the primary researcher, service-users, and clinicians, however, due to a break in the study and the impact of COVID 19 the initial working group disbanded, and a new working group was formed. The new working group consisted of three clinicians and the primary researcher, this group were responsible for the analysis, interpretation, and dissemination of the research. In line with the 'Ladder of Co-production' by the National Co-production Advisory Group (NCAG) there was an equal relationship between all within the coproduction group members with shared decision making a cornerstone throughout the project. This approach went beyond Patient and Public Involvement (PPI) methods of consultation on study design and management.

Participants and recruitment

Nine clinicians were recruited from one mental healthcare organisation to examine the role of clinicians and social culture within a defined community. Participants had a range of community and inpatient experience and included: Assistant Psychologist, Occupational Therapist (OT), OT assistant, Student Nurses (2), Mental Health Nurses (2), Nurse specialist, and a Research Nurse. The participants included those who were early in their career as well as senior practitioner leaders with many years of experience.

Participants were recruited via the GLCN through snowballing recruitment to clinical teams using GCLN representatives. The study poster (Appendix F) and participant information sheets (Appendix G) were sent to 195 representatives in the GLCN to disseminate to their clinical teams/area of organisation. The study poster was also included in the trust e-newsletter which was sent to over 5000 staff members. Potential participants were requested to contact the primary researcher via email. On expression of interest from a clinician, a face-to-face Semi Structured Interview (SSI) was arranged where formal consent was gained prior to the interview start.

Inclusion criteria

- Registered and non-registered clinicians who have face to face, ongoing contact with service users
- Minimum of one year's experience working clinically within mental health services
- Experience of working in mental health settings with individuals who have literacy difficulties, but not limited to individuals living with learning disabilities

Exclusion criteria

- Less than one year's experience of working within mental health services or with experience only within specialist learning disability services
- No face to face, ongoing contact with service users
- Clinicians that are unwilling to provide consent to take part in qualitative interviews

Data collection materials

The interview topic guide (Appendix H) was developed in the co-production working group. The working group were presented with the theory and the existing relevant literature prior to meeting together as a group. The topic guide allowed for flexibility so participants could lead the direction of the interview and discuss what they felt was most important. The topic guide started with a general open statement, 'Tell me about your experiences of working with people who have literacy needs', followed by more specific questions, such as, 'How did you make adjustments to involve these individuals in their care?', designed to elicit more in-depth detail. Interview questions were grouped into three key areas: Clinician's experience, Societal factors, Change and improvement. A short questionnaire containing non-identifiable demographic information was also created to capture if the participants demonstrated a range of different professional characteristics (Appendix I).

Procedure

Semi structured interviews took place at the participant’s place of work or over the phone/ via video call. There was a minimum of 48 hours between the information sheet being received and interviews taking place. The interview was carried out by the primary researcher and consisted of gaining formal informed consent for participation and audio recording (Appendix J), collecting demographic and relevant experience information, completing the SSI, and time for a debrief.

Data from the interviews were transcribed verbatim from audio recordings by the primary researcher. Transcripts were checked for accuracy by an independent reviewer. Thematic analysis (Braun and Clark, 2013) was used to analyse this qualitative data. Specifically, the framework analysis method described by Gale et al. (2013) was used given its appropriateness for semi-structured interviews within health research. This approach also encourages multiple perspectives from people who don’t need to have prior qualitative research experience, which enabled the co-production group to be an integral part of the analysis process. The co-production working group were involved in the whole analysis process including coding, developing an analytical framework, applying the framework, and interpretating the data. All transcripts were analysed by the primary researcher and at least one other member of the co-production working group. The working group helped with the initial coding and development of themes. The working group then arranged the codes to reflect themes with agreed names and definitions.

This study was carried out in accordance with the BPS Code of Conduct and Ethics (2009). Local ethical approval from the University of East Anglia Faculty of Medical Health ethics was gained (Appendix K) and the study was registered and approved by the Health

Registration Authority (Appendix L). All identifiable information was removed during the transcription process.

Results

The experiences shared by the mental health clinicians in this study were represented by 5 overall themes developed by the co-production working group: Intersectionality; Clinician Attitude; Humanistic Approach; Service provision; and Social inequality. The co-production team identified superordinate themes and subordinate themes sitting under them, see Table 4.1. A diagrammatic representation of these themes can be found in Appendix M. It is recognised that in being co-produced, the themes generated represent both the views and experiences of the participants as well as the working group. Both of these groups are mental healthcare professionals working within a specific organisational and social culture. Therefore, the themes emerging from the interview data will have been constructed as influenced by the shared reality and interactions of these groups of people.

Table 4.1: Superordinate and subordinate themes

Superordinate themes	Subordinate themes
Intersectionality	Mental health impacts on cognition for literacy skills
	Literacy difficulties impact on mental health (internalised)
	Holistic impact of literacy difficulties and consequent impact on identity (self-stigma)
	Mental health can overshadow literacy difficulties (unmet need)
	Impact of literacy difficulties becomes more complex as people age
Clinician attitude	Strong emotional response
	Multiple pressures on clinicians lead to literacy not being a priority
	Needing to go the extra mile
	Clinicians not feeling like they're able to care in the 'right' way
	Perceptions of literacy being difficult to ask about
Humanistic approach	Importance of a whole person approach/ holistic assessment
	Importance of a trusting relationship between clinician and service user

Table 4.1: Superordinate and subordinate themes	Clinician's awareness of literacy difficulties (internal)
	Need to ask about literacy difficulties (actional)
	Working with service users/experts by experience to inform service improvement
	Being creative
Service Provision	Services assume good literacy skills when communicating
	Unmet literacy needs means service users are more likely to disengage
	Negative impact on care journey and outcomes (discharge, capacity, and medication)
	Lack of agency for clinicians due to gaps in resources/training/materials
	Unknown literacy difficulties a barrier to person-centred care
	Iatrogenic harm resulting from service delivery
Social inequality	Negative views of literacy difficulties in society placing people with literacy difficulties as outside the norm
	Internalised fear of not being accepted or valued within society
	Systemic barriers to achieving life goals for those with literacy difficulties (Social stigma)
	Clinician’s role in needing to challenge society’s views

Within this paper the focus will be on the themes of ‘Humanistic approach’ and ‘Service provision’ the two themes most relevant to clinical practice and implications. Humanistic approach describes the 1:1 relationship between clinician and service user that enables person-centred care, whilst service provision recognises the importance of structures at a system level to enable individual clinicians to deliver person-centred care. The other themes will be briefly described, with a fuller exploration of these themes available in Appendix N.

Humanistic Approach

Participants described how a humanistic approach could empower individuals with literacy difficulties within mental health services. They described an ongoing individualised approach that encompasses a willingness for flexibility with a focus on connection over procedure, and curiosity over assumptions whilst recognising individuals’ inherent value.

Participants reflected on how this approach can help to address some of the barriers experienced by those with literacy difficulties.

Importance of a whole person approach/ holistic assessment

Participants viewed a humanistic approach as central to delivering person-centred care. Participants reflected on how they found a whole person approach could be used to fully meet an individual's needs and this would encompass someone's literacy needs.

> It is that that person struggles with, so it's going to be different for everyone, it's not going to be the same thing for each person (p4)

> I guess it's an observation, almost you don't have to ask them, you kind of its your clinical intuition, you get a feel for what someone is saying. Communication isn't necessarily just through verbal kind of bits, certainly with OT there is lots of observations, yours assessing from the minute you meet them, and they don't have to always say stuff (p2)

Importance of a trusting relationship between clinician and service user

Participants described how important they felt a therapeutic relationship was to build trust and create an environment in which someone would feel comfortable to discuss their needs, including their literacy needs.

> You need to create the environment in which people would tell you (p6)

> You've got to get a bit of rapport and you know…you could probably do it in the first assessment, I think I often do (p9)

> Once you start to build up a bit of a relationship with people they will open up (p5)

Clinician's awareness of literacy difficulties

Participants reflected on the importance of a general awareness of literacy difficulties and how they might impact on an individual and their journey through care systems. Participants spoke about how they felt some clinicians may have greater awareness of literacy difficulties if this is something that they have personal or professional experience of.

> Identify what you think might be an additional need which I think literacy problems are you can then offer additional support (p8)

> The way I work with them is influenced by, I used to work on an LD [learning disability] ward so I use some of the same strategies and techniques (p1)

> I think actually it needs to be addressed with awareness so awareness and then additional training (p8)

Need to ask about literacy difficulties

Participants expressed multiple ideas around identifying if an individual has literacy needs. Some participants spoke about how important they felt it was for clinicians to be asking individuals about their literacy needs. However, it was also identified that participants often felt the need to sometimes be 'detectives', continually assessing and picking up on subtle cues that might indicate that someone has literacy difficulties.

> First and foremost you ask them (p2)

> I think we need to be a lot quicker, I think we need to be more aware of asking that question, I don't think enough people ask…perhaps that needs to be one of the questions on the assessment that we ask 'can you read and write Ok' (p7)

> If they're not asked, its pretty key… If you don't ask you wouldn't know maybe. (p6)

> I like to sit and speak with people because through their terminology you can acknowledge and assess quite a lot, through their structure of sentences, through their social cues, pauses (p8)

Utilising service users/experts by experience

Participants suggested that it would be useful to work with service users to co-develop services. They recognised that co-production in services is important to ensure that we learn from those with lived experience.

> Co-production is a good place to start, don't assume that we as an organisation know the best way to do things or to describe things for people with lived experience because we don't, we need to ask people (p6)

> I always think it's nice if they are able to see other examples of people with similar issues (p1)

Being creative

Participants provided examples of how they work creatively to make adjustments to provide person-centred care and meet the needs of individuals with literacy difficulties. There were examples of current practice that participants are doing to adapt and tailor their approach to meet an individual's needs, including using photographs, drawings, and videos.

> You might even look to draw pictures, engage in art, there are other ways of finding out what people want but you do have to be a bit creative about it (p2)

> It is about adapting your approach… working with that person to identify how best are you actually going to be able to take this information on board (p3)

> Try and identify their needs and how they can have their needs met, so really to put it maybe too simply its about finding a way to do that, that works for someone that's in whichever sort of stage of their mental illness or having needs for their mental health coupled with the literacy difficulties, its just finding a way to still do that, tailored for that individual and their specific needs (p3)

Service provision

Participants reflected on how they felt that service structures are often based on assumptions of literacy and in doing this mental health organisations risk disempowering and causing potential iatrogenic harm to those with literacy difficulties.

Services assume good literacy skills when communicating

Participants discussed feeling that services are delivered in a way that often assumes literacy capabilities from service users. They reflected on how they felt that due to this assumption of literacy services are often not accessible to those who have extra needs.

> Everything that we do is around words, a lot of it is around writing…if you disengage from us and I send you an opt in letter in the post, if you can't read it, that's worthless, so you're not going to know that I'm trying to get hold of you because you've been referred and I need to make contact. Everything is heavily reliant on letters or written communication (p3)

> Not making assumptions that everyone's going to find something that you think is really straight forward is going to be straightforward for them. (p6)

> I think sometimes we need to seek it out a little bit more, still as a professional I am reminded all the time that I tend to assume people can read and write (p8)

Unknown literacy difficulties a barrier to person-centred care (due to services not asking)

Participants reflected on how an assumption of literacy in services, in combination with clinicians not asking about literacy difficulties, can lead to literacy difficulties being unidentified. Participants suggested that if we do not know about an individual's literacy needs this creates a barrier to delivering truly person-centred care.

> Been given some information about mindfulness or autism and you go away and read that but actually you haven't checked to see whether they can read that first, so they might just stick it in the recycling bin (p7)

> Another sort of issue that we come up against is around signposting, a lot of it is around leaflets and giving people sort of information, and obviously if I can't, say if I can't read at all and you give me a leaflet, unless I make you aware that I can't read I'm not going to do anything with that leaflet. (p3)

> Some of the language is discriminatory, stigmatising, difficult to read difficult to understand (p6)

Unmet literacy needs means service users are more likely to disengage

Participants described how whilst services may not intentionally discriminate against those with literacy difficulties, the way that systems work may mean someone could encounter difficulties from the beginning in navigating mental health services if they have extra literacy needs. Several participants reflected on how services that are inaccessible may lead to people disengaging with the service even when they really need it.

> All heavily based around literacy, which I think you run the risk of alienating the people who have difficulty with their literacy by doing it that way (p3)

> You say you just need this leaflet or you just need this leaflet then eventually they're going to drop away, they're not going to be interested, it's not going to hold them, it's not going to do anything for them, and I think you know we stand a chance of losing people …that's where we're gunna end up, with people who really really need help choosing not to engage because they can't engage fully with it (p7)

> I also think it's a massive barrier to engagement in service initial engagement, a phonecall to give an appointment and then an appointment letter in easy read just in general for all client groups is probably quite successful as opposed to a letter without initial contact and spoken communication. And NHS letters can be quite threatening to people who don't understand (p8)

Negative impact on care journey and outcomes (discharge, capacity, and medication)

Some participants discussed the potential for negative consequences beyond disengagement with care, thinking about the impact of services assuming literacy on the wider care journey and outcomes. Participants gave examples of when they had seen this happen, these included inappropriate medication administration, prolonged discharges, and inappropriate capacity assessments.

> He was on a section and he wanted to appeal but he struggled to do that because of reading the information that was provided to him, and at first he was too embarrassed to tell anyone that he couldn’t read and write so he didn’t seek any support, he was just agreeing to things that maybe he wouldn’t have agreed to if he had been able to read the information given. (p4)

> I asked him if he knew the names of his medication, and he didn’t. I asked him if he knew what his medication was for, and he didn’t. I asked him if he was able to read the information leaflets that come in the boxes with the medication, and he didn’t understand. I asked him if he was taking his medication, he said that he wasn’t because he didn’t know what time of day he was supposed to take them, and all of this had been presumed by the professionals involved (p8)

> You know that could lead to all sorts of problems…you’re handing people bags of drugs with the writing on the outside, you know how to follow taking your medication. (p9)

Iatrogenic harm

Participants spoke about their reflections on how services that are not accessible to those who have extra needs may inadvertently mirror the difficulties that people experience within society, thus potentially causing iatrogenic harm and disengagement from healthcare.

> I'd imagine that the idea of homework is going to have an association that is not particularly positive and put you back in the space of being a failure (p1)

> If you just launch straight in with that expectation, bombard them with literature, which we do and we haven't checked…then you're potentially gunna negatively affect their mental health, possibly affect engagement as well (p7)

> In absolute honesty I think there's a level of shame, I think because professionals presume and that shame kicks in even more (p8)

> I think it's because it's a difference and it's presumed so much that it becomes disempowering to them and they notice the absence and feel different for it maybe (p8)

Lack of agency for staff due to gaps in resources/training/materials

Participants also spoke about how not all clinicians might feel confident working with literacy difficulties. Participants felt that some clinicians might experience a lack of agency due to a lack of knowledge/expertise working with individuals with literacy difficulties or not feeling they have the appropriate resources to support people with literacy needs. Some participants described how they felt organisations should consider reasonable adjustments for clinicians with literacy needs too.

> I think most people are pretty good about identifying if someone has a literacy difficulty but what do we then do about it (p2)

> It’s kind of difficult to know what else you could provide as such but I guess if we had more training then we would know more what we would need to provide (p4)

> I think that’s really the issue, its resource availability so you know if you do uncover a problem you’ve got a solution for that difficulty and that problem and I think that’s one of the big issues you don’t want to ask a question and get the wrong answer do you and cause more issues (p7)

Intersectionality

Participants described how they viewed the combination and interdependence of literacy difficulties and mental health difficulties on each other creates a global impact on an individual’s life and identity.

Clinician attitude

Participants described an emotional response to difficulties faced by individuals with literacy difficulties and the need to go the extra mile to advocate for them. Participants also reflected on how they felt staff pressures and service structure meant they could not always provide appropriate person-centred care.

Social Inequality

Participants strongly indicated that they felt society creates a stigma and discriminates against those with literacy difficulties, leading them to experience cultural and structural barriers to comprehensive inclusion in life.

Discussion

This co-produced study provides us with some insights into the experiences of mental health clinicians working with individuals who have literacy difficulties. It provides some understanding of current perceived barriers to person-centred care for those with both mental health and literacy difficulties as well as facilitators for empowering these individuals within this mental health organisation. It also begins to explore the processes that may be at play for an individual with literacy difficulties navigating mental health services through the perceptions of clinicians. The results from this study help us to understand more about the interaction between literacy and mental health within practice, particularly within this organisation.

Participants suggested that society's negative views around literacy difficulties can lead to internalised stigma that leaves people feeling shameful or embarrassed about their literacy skills and fearful of how others might judge them consequently. Prior literature supports these reflections; Luoma and Platt (2015) describe how having a stigmatised identity can lead individuals to feeling devalued, shamed, and negatively impact on social engagement and connection. These difficult feelings as result of internalised stigma may mean service users try to hide their literacy difficulties. Rivera-Segarra and Ramos-Pibernus (2013) proposes that stigma, recognised as a social process, should be conceptualised as a social determinant of health. Hatzenbuehler et al. (2013) provides evidence to support these ideas that stigma is a fundamental cause of both physical and mental health inequalities. This social constructionist study adds to the existing literature suggesting that the negative views created and maintained in society around low literacy can create both social and internalised stigma which may also be impacting on mental health outcomes.

Participants also reflected on how those with literacy difficulties often experience perceived systemic barriers to achieving their desired life goals, Ahmedani (2011) suggests that social stigma leads to embedded inequalities within social frameworks. This sense of systemic barriers to progressing in life were linked back to the intersectionality of literacy and mental health. Collins and Bilge (2020) describe intersectionality as how within society elements of power relations are not mutually exclusive but build on each other and work together. They identify how the intersecting nature of these different power relations impacts on all aspects of an individual's social world.

Within this study, participants identified that services are often developed with an intrinsic assumption of literacy which often renders them inaccessible to some individuals. It may be that service gaps are present due to the identified intrinsic stigmas within society around literacy difficulties. Halford et al. (2019) describe how the way in which healthcare systems are organised gives privilege to those who fit the system and may further disadvantage those with existing health inequalities. The way in which services are structured can lead to disempowerment of service users and have some potentially serious outcomes on an individual's journey within services, which was reflected in this current study. It may be that this sense of feeling disempowered, identified by participants in this study, by inaccessibility and an organisational assumption of literacy is aligning with an individual's previous experiences of stigma in society. Dobransky (2019) found that mental health care providers play an important role in stigma management. They recognised that whilst providers support clients to manage stigma through 'normalising' and 'brokering/buffering', some attempts at stigma management may unintentionally increase the stigma experienced by making the mental health status of a service user more widely known. Wang et al. (2018)

highlighted how perceived stigma from services can contribute to feelings of disempowerment within mental health services, particularly when negative beliefs were internalised. Given that there is a possible complex stigma for those with literacy and mental health difficulties (Lincoln et al. 2017) the risk of disempowerment may be even greater for this client group. Participants in the present study recognised that in services not accounting for low literacy abilities, services may in fact be at risk of causing iatrogenic harm to individuals through reinforcing existing internalised or felt stigma.

The participants in this study reflected on the role that stigma can play within person-centred care. They described how their experiences led them to feel that gaps in service provision and literacy often going unrecognised could lead to unmet needs and a lack of truly person-centred care. In order to maintain a person-centred approach, participants expressed the importance of holistic assessments that take into account literacy needs both by explicitly asking and taking a more subtle approach, picking up on indicators that literacy might be a challenge, for example if an individual is avoiding written information. Prior research indicates conflict about literacy screening within health settings. Paasche-Orlow and Wolf (2008) argued that literacy screening has the potential to cause harm through shame and alienation and cautioned against it. Indeed, some participants within the current study identified that asking individuals about their literacy difficulties often felt really difficult, perhaps reflecting the wider stigmas within society. However, research where literacy screening has been embedded as part of routine practice has been found to be useful in identifying those with low health literacy (Heinrich 2012; Komenaka et al. 2014) and has not found to impact negatively on patient satisfaction. In line with this, participants in the current study identified that having a non-judgemental approach and holistic assessment of needs may reduce the shame of asking individuals about difficulties with literacy.

Participants also highlighted the need for building a trusting relationship to support people with literacy needs, supporting prior work (Epstein et al. 2010; Hamovitch et al. 2018) which suggests that a therapeutic relationship is an essential part of providing person-centred care and enabling engagement. Ekman et al. (2011) expand on the importance of relationship within person-centred care and suggest that by inviting an individual to give their narrative it indicates to the service user that their feelings, experiences, beliefs, and preferences are valid and important. In turn this allows open communication which then enables better care and treatment. This process of therapeutic relationships allowing individuals to share their narrative and feel empowered within services, and in turn allowing more accessible and appropriate care for an individual, was frequently covered by participating clinicians. This was also reflected in the way that clinician participants described strong emotions connected to empowering individuals through this therapeutic relationship and meeting individual's needs.

This research highlights the importance of clinicians' understanding and acknowledgment of an individual's literacy difficulties within mental health settings. It suggests that the way in which literacy difficulties are discussed and treated within society can potentially impact on both an individual's own experiences and how services respond to those with literacy difficulties. Whilst mental health services are not literacy educators, it reflects the importance of both individual clinicians and services as a whole working to develop ways to reduce inequalities around literacy within mental health services to empower service users. In line with a person-centred approach, by recognising literacy difficulties and taking actions to support individuals in a non-stigmatising, accessible way, we are more likely to be able to meet individuals needs and help promote their recovery. It is important that services support clinicians, in both their skills and their confidence, to be able to offer appropriate person-centred care.

It is recognised that all participants within this study had experience of identifying and working with service users with literacy needs. This suggests that the participants had a certain level of awareness of literacy difficulties in mental health services and thus the results may not reflect the general level of awareness of literacy difficulties within the service.

Future Direction

This study has examined how literacy and mental health difficulties may impact experience of mental health care from the perspective of healthcare professionals. Due to the fact that within this organisation services don’t currently identify or record uniformly when a service user has a literacy difficulty, we were unable to include the perspectives of those who are navigating this complex layered interaction themselves. In order to fully understand how those with literacy difficulties experience mental health services, it is imperative that future research explores lived experience of service users too.

It is important to recognise that participants within this study were only from one organisation. Whilst a richness of information was gathered from the 9 participants, with different professional backgrounds, the results from this study are context specific and present an insight into beliefs of a particular set of clinicians within one organisation. It is acknowledged that the culture and language within this organisation is likely to have shaped and informed the clinicians’ responses. Future research could look to expand the findings by looking at clinicians’ perspectives more broadly across a wider range of clinicians and including other mental health organisations where staff cultures may be different.

REFERENCES

Ahmedani, Brian K. 2011. "Mental health stigma: society, individuals, and the profession." *Journal of social work values and ethics* 8(2):4-1.

Arnold, Elizabeth Mayfield, David B. Goldston, Adam K. Walsh, Beth A. Reboussin, Stephanie Sergent Daniel, Enith Hickman, and Frank B. Wood. 2005. "Severity of emotional and behavioral problems among poor and typical readers." *Journal of abnormal child psychology* 33(2):205-217.

Bass III, Pat F., John F. Wilson, Charles H. Griffith, and Don R. Barnett. 2002. "Residents' ability to identify patients with poor literacy skills." *Academic Medicine* 77(10):1039-1041.

Bensing, J., Peter FM Verhaak, Alexandra M. van Dulmen, and Adriaan Ph Visser. 2000. "Communication: the royal pathway to patient-centred medicine." *Patient Education and Counseling* 39:1-3.

Boyes, Mark E., Suze Leitao, Mary Claessen, Nicholas A. Badcock, and Mandy Nayton. 2016. "Why are reading difficulties associated with mental health problems?" *Dyslexia* 22(3): 263-266.

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

Brooks, Charlotte, Claire Ballinger, Don Nutbeam, Clare Mander, and Jo Adams. 2018. "Nursing and allied health professionals' views about using health literacy screening tools and a universal precautions approach to communication with older adults: a qualitative study." *Disability and rehabilitation* 1-7.

Bynner, John, and Samantha Parsons. 2006. *New light on literacy and numeracy*. National Research and Development Centre for Adult Literacy and Numeracy. London.

Chan, Kevin KS, and Winnie WS Mak. 2014. “The mediating role of self-stigma and unmet needs on the recovery of people with schizophrenia living in the community.” *Quality of Life Research* 23(9): 2559-2568.

Collins, Patricia Hill, and Sirma Bilge. 2020. *Intersectionality*. John Wiley and Sons.

Cooper, Mick. 2008. *Essential research findings in counselling and psychotherapy: The facts are friendly*. Sage.

Corrigan, Patrick. and Deepa Rao. 2012. “On the self-stigma of mental illness: Stages, disclosure, and strategies for change.” *The Canadian Journal of Psychiatry*, 57(8):464-469.

Corrigan, Patrick W., Benjamin G. Druss, and Deborah A. Perlick. 2014. “The impact of mental illness stigma on seeking and participating in mental health care.” *Psychological Science in the Public Interest* 15(2):37-70.

Department for Business Innovation and Skills. 2015. *International Evidence Review of Basic Skills survey in 2015.*

Dobransky, Kerry Michael. 2019. "Breaking down walls, building bridges: Professional stigma management in mental health care." *Society and Mental Health* 9(2):228-242.

Easton, Phyllis, Vikki A. Entwistle, and Brian Williams. 2013. “How the stigma of low literacy can impair patient-professional spoken interactions and affect health: insights from a qualitative investigation.” *BMC health services research* 13(1):319.

Eissa, Mai. 2010. “Behavioral and emotional problems associated with dyslexia in adolescence.” *Current Psychiatry* 17(1): 39-47.

Ekman, Inger, Karl Swedberg, Charles Taft, Anders Lindseth, Astrid Norberg, Eva Brink, Jane Carlsson et al. 2011. "Person-centred care—ready for prime time." *European journal of cardiovascular nursing* 10(4):248-251.

Epstein, Ronald M., Peter Franks, Kevin Fiscella, Cleveland G. Shields, Sean C. Meldrum, Richard L. Kravitz, and Paul R. Duberstein. 2005. “Measuring patient-centred communication in patient–physician consultations: theoretical and practical issues.” *Social science and medicine* 61(7):1516-1528.

Epstein, Ronald M., Kevin Fiscella, Cara S. Lesser, and Kurt C. Stange. 2010. "Why the nation needs a policy push on patient-centred health care." *Health affairs* 29(8):1489-1495.

Francis, Deanna A., Nathan Caruana, Jennifer L. Hudson, and Genevieve M. McArthur. 2019. "The association between poor reading and internalising problems: a systematic review and meta-analysis." *Clinical Psychology Review* 67:45-60.

Frost, David. 2011. “Social stigma and its consequences for the socially stigmatized.” *Social and Personality Psychology Compass* 5(11):824-839.

Gale, Nicola K., Gemma Heath, Elaine Cameron, Sabina Rashid, and Sabi Redwood. 2013. “Using the framework method for the analysis of qualitative data in multi-disciplinary health research.” *BMC medical research methodology* 13(1):1-8.

Gask, Linda, and Peter Coventry. 2012. “Person-centred mental health care: the challenge of implementation.” *Epidemiology and psychiatric sciences*, 21(2):139-144.

Goldberg, Daniel S. 2017. "On stigma & health." *Journal of Law, Medicine & Ethics,* 45(4):475-483.

Halford, Susan, Alison Fuller, Kate Lyle, and Rebecca Taylor. 2019. "Organizing health inequalities? Employee-driven innovation and the transformation of care." *Sociological research online* 24(1): 3-20.

Hamovitch, Emily K., Mimi Choy-Brown, and Victoria Stanhope. 2018. "Person-centred care and the therapeutic alliance." *Community mental health journal* 54(7):951-958.

Hatzenbuehler, Mark L., Jo C. Phelan, and Bruce G. Link. 2013. "Stigma as a fundamental cause of population health inequalities." *American journal of public health* 103(5):813-821.

Heinrich, Carol. 2012. "Health literacy: The sixth vital sign." *Journal of the American Academy of Nurse Practitioners* 24(4):218-223.

Herek, Gregory. 2009a. Sexual prejudice. In T. D. Nelson (Ed.), *Handbook of Prejudice, Stereotyping, and Discrimination.* Psychology Press. New York, Hove

Jacobs, Heidi Hayes. 2014. "Active literacy across the curriculum: Strategies for reading, writing, speaking, and listening." Routledge. New York.

Jenkins, Janis. and Elizabeth Carpenter-Song. 2008. "Stigma despite recovery: Strategies for living in the aftermath of psychosis." *Medical Anthropology Quarterly*, 22(4):381-409.

Komenaka, Ian K., Jesse N. Nodora, Lorenzo Machado, Chiu-Hsieh Hsu, Anne E. Klemens, Maria Elena Martinez, Marcia E. Bouton, Krista L. Wilhelmson, and Barry D. Weiss. 2014. "Health literacy assessment and patient satisfaction in surgical practice." *Surgery* 155(3):374-383.

Literacy Trust. 2012. Adult Literacy Statistics: Retrieved January 25, 2022 (https://literacytrust.org.uk/parents-and-families/adult-literacy/)

Lee, Judith. 2001. *The empowerment approach to social work practice*. Columbia University Press. New York

Lincoln, Alisa, Wallis Adams, Mara Eyllon, Suzanne Garverich, Christopher Prener, John Griffith, Michael Paasche-Orlow, and Kim Hopper. 2017. "The double stigma of limited literacy and mental illness: Examining barriers to recovery and participation among public mental health service users." *Society and Mental Health*, 7(3):121-141.

Luoma, Jason B., and Melissa G. Platt. 2015. "Shame, self-criticism, self-stigma, and compassion in acceptance and commitment therapy." *Current opinion in Psychology* 2:97-101.

Meisenbach, Rebecca. 2010. “Stigma management communication: A theory and agenda for applied research on how individuals manage moments of stigmatized identity.” *Journal of Applied Communication Research* 38(3):268-292.

Morgan, Paul., George Farkas, and Qiong Wu. 2012. “Do poor readers feel angry, sad, and unpopular?” *Scientific Studies of Reading* 16(4):360-381.

NHS England. 2019. “NHS Long Term Plan.” *London, England:* Retrieved from https://www.longtermplan.nhs.uk

Needham, Catherine. 2008. "Realising the potential of co-production: Negotiating improvements in public services.*" Social policy and society* 7(2):221-231.

Paasche-Orlow, Michael K., and Michael S. Wolf. 2008. "Evidence does not support clinical screening of literacy." *Journal of general internal medicine* 23(1):100-102.

Pachankis, John E. 2007. "The psychological implications of concealing a stigma: a cognitive-affective-behavioral model." *Psychological bulletin* 133(2):328.

Parikh, Nina., Ruth Parker, Joanne Nurss, David Baker, and Mark Williams. 1996. “Shame and health literacy: the unspoken connection.” *Patient education and counseling* 27(1): 33-39.

Patel, Sonal, and Ros Dowse. 2015. “Understanding the medicines information-seeking behaviour and information needs of South African long-term patients with limited literacy skills.” *Health expectations: an international journal of public participation in health care and health policy* 18(5):1494–1507.

Realpe, Alba, and Louise Wallace. 2010. “What is co-production.” *London: The Health Foundation* 1-11.

Rivera-Segarra, Eliut, and A. Ramos-Pibernus. 2013. "Stigma as a social determinant of health: A fundamental cause theory perspective." *Social Inclusion Trough Interdisciplinary Interventions*: 1027-1030.

Roth, Dee, and Dushka Crane-Ross. 2002. “Impact of services, met needs, and service empowerment on consumer outcomes.” *Mental Health Services Research* 4(1):43-56.

Sentell, Tetine L., and Martha A. Shumway. 2003. "Low literacy and mental illness in a nationally representative sample." *The Journal of nervous and mental disease* 191(8):549-552.

Schillinger, Dean. 2020. "The intersections between social determinants of health, health literacy, and health disparities." *Studies in health technology and informatics* 26: 22.

Social Care Institute for Excellence. 2013. “Co-production in social care: What it is and how to do it” *SCIE Guide* 51.

Snowling, Margaret J., Valerie Muter, and Julia Carroll. 2007. “Children at family risk of dyslexia: a follow-up in early adolescence.” *Journal of child psychology and psychiatry* 48(6):609-618.

Tongue, John R., Howard R. Epps, and Laura L. Forese. 2005. "Communication skills for patient-centred care: research-based, easily learned techniques for medical interviews that benefit orthopaedic surgeons and their patients." *Journal of Bone and Joint Surgery* 87(3):652-658.

Vijayalakshmi, Poreddi, Ramachandra, Konduru Reddemma, and Suresh Bada Math. 2013. "Perceived human rights violation in persons with mental illness: Role of education." *International journal of social psychiatry* 59(40):351-364.

Vogel, David L., Rachel L. Bitman, Joseph H. Hammer, and Nathaniel G. Wade. 2013. "Is stigma internalized? The longitudinal impact of public stigma on self-stigma." *Journal of counseling psychology* 60(2):311.

Wang, Katie, Bruce G. Link, Patrick W. Corrigan, Larry Davidson, and Elizabeth Flanagan. 2018. "Perceived provider stigma as a predictor of mental health service users' internalized stigma and disempowerment." *Psychiatry research* 259:526-531.

Whitehouse, Andrew JO, Tim D. Spector, and Lynn F. Cherkas. 2009. "No clear genetic influences on the association between dyslexia and anxiety in a population-based sample of female twins." *Dyslexia* 15(4):282-290.

Wolf, Michael S., Mark V. Williams, Ruth M. Parker, Nina S. Parikh, Adam W. Nowlan, and David W. Baker. 2007. "Patients' shame and attitudes toward discussing the results of literacy screening." *Journal of health communication* 12(8):721-732.

Zhang, Qiyang. 2021. "The cost of illiteracy: A causal inference study on how illiteracy affects physical and mental health." *Health Education Journal* 80(1):54-66.

Chapter Five

Additional Methods

Additional Methods

This chapter will explore the methods reported in the empirical paper in more detail. In particular, it will discuss the researcher's epistemological stance in the empirical project. It will present a concise overview of the social constructionist stance and how this was relevant to this project. It will also provide a brief background as to how co-production was understood within the current project and how it was utilised within this empirical project methodology. The chapter will then detail the analysis process and include an example of an extract from an unidentifiable transcript to demonstrate the analysis process. Finally, the chapter will document how quality was maintained within the current study.

Epistemology

Social constructionism is based on the assumption that an individual's reality, or what they understand to be reality, is constructed by people within their specific social contexts (Jankowski, Clark & Ivey, 2000) and is historically and culturally specific (Lester & O'Riley, 2021). Berger and Luckmann (1966) were influential in the development of social constructionism; they suggested that social reality is created through individuals' actions and interactions. They describe the process in which exchanges between individuals and their social systems over time become shared and habituated and this understanding is embedded within society. Within this framework, social constructionist researchers are interested not just in what a phenomenon is, but in how the phenomena is perceived (Harper, 2011).

Relevance to the current study

Given the emphasis within a social constructionist stance on the role that language plays in the construction of knowledge and culture it is perhaps not surprising that it has often become the theory of choice within the field of literacy (Sullivan, 1995), and was of relevance in the current study. Through a social constructionist lens, language is not just a way of interacting with others but it is within language that individuals exist. This study was concerned with how literacy impacts on experiences within mental health services. Thus, beyond its appropriateness within literacy research, taking a social constructionist approach also allowed for recognition of the meaning making that happens between clinicians and service users within a social context, particularly within the framework of providing person-centred care. By taking this stance it highlighted that the roles and values of both the clinician and service user are not determined but constructed through their joint interactions (Ishikawa, Hashimoto & Kiuchi, 2013). This empirical project was concerned with a group of people, with a shared characteristic of being a mental health clinician, and how they perceive and understand the interactions within a specific social context, an NHS mental health care organisation in the East of England. A social constructionist stance was fitting with this exploration of interactions within this social system and the wider role that local organisation and society culture has on these interactions.

This social constructionist stance also fitted with the co-production methodology utilised given that social constructionism recognises that instead of there being one clear truth there is a reality that is developed by contributions from all within that context. Rycroft-Malone et al. (2016) describe how the shift in healthcare towards co-production of knowledge represents a move towards socially constructed and embedded views where knowledge is generated within the context in which it will be used. Filipe, Renedo and Marston (2017) suggest that co-production is best seen as generative process that goes beyond delivering predictable outputs and is more concerned with developing new communities, interactions, and practices. The current research project aimed to use co-production to understand the meaning clinicians jointly bring to the experiences of those with literacy difficulties within the specific context of mental health services. Over and above the research outcomes, the project in itself hoped to develop new conversations and practices around literacy difficulties bringing awareness of this important issue into awareness in the context in which it took place.

Impact on research methods

Gergen (2004) identifies core values of social constructionist research methods as: valuing reflection; legitimising the subject voice; collaborative participation; multiple standpoints, and representational creativity. In line with this, the researcher aimed to incorporate all these values within the empirical project. By utilising co-production methodology, the project aimed to allow the voice of clinician's to be heard in multiple ways. The focus of this research was clinician perspectives, this was captured both by the participants within the research as well as the co-production group. Further to this, co-production also allowed for collaborative participation whereby clinicians were invited to be part of the generation of knowledge with an aim for them to benefit from the outcomes of the research too. Those involved in the co-production group saw their participation as professional development as well as an opportunity to contribute towards future service improvement initiatives. When considering representational creativity in the design phase of the research study it was decided that results from the research would be disseminated in various formats, including video, in order to increase its accessibility.

Parton (2003) suggest that from a social constructionist view it is important for the researcher not to take an expert stance but instead to develop a stance of 'not knowing'. Jankowski et al. (2000) argue that taking a 'not knowing' stance helps to address issues of power, creating an equality within the research, and allows a researcher to recognise points of convergence and divergence with existing knowledge. The co-production methodology within this project allowed for a rebalancing of hierarchies and encouraged this 'not knowing' stance from the primary researcher. The primary researcher was included as an equal member of the co-production group rather than having a hierarchical status. In doing this, knowledge was sought from those within the context of which the project was situated. Jankowski et al. also describe how in taking a social constructionist approach the researcher must take a shift away from gathering data that fits specified models or theories and instead seek for a context in which the participants experiences can become part of a conversation. The researcher was careful within both co-production meetings and within the semi-structured interviews with participants to be aware of their own stance and encourage both participants and the co-production group to share their views and experiences without leading them to particular responses that would conform to the researcher's existing understanding and hypothesis.

This social constructionist stance was present from the conception of the project. When developing the research question and aims there was an emphasis on understanding how the intricacies of literacy and mental health are perceived and described by clinicians rather than trying to find an objective truth (Lindgren & Packendorff, 2009). Further to this, the choice to explore person-centred care within the research question reflected how an individual experiences services not in isolation but in a social context where interactions between service users and clinicians influence an individual's experience of mental health care. Choosing to explore clinician experiences from one mental health organisation, rather than multiple organisations, was a reflection of the understanding that an individual's reality is specific to their culture and context (Burr & Dick, 2017). Each mental health organisation will have its own unique culture and this context is likely to impact on an individual's experience.

In the interview process, the topic guide was used as a prompt for covering what had been identified as relevant by the co-production working group. However, to reflect the social constructionist epistemology and the desire to have a joint construction of knowledge from all involved, the interviewer sought to balance the power by following the interviewees' lead and having a conversational approach enabling questions to be born from the participants answers (Losantos et al. 2016). The social constructionist stance also recognised that within the analysis process the co-production working group will have pulled out elements that resonated with their own truth and experiences. The working group reflected on how instead of there being one definitive truth to be found in the data, the reality of the phenomena being explored is developed through a communal process (Slater, 2017), including both the participants and the members of the working group. Thus, the interpretation of the data represents a shared understanding of groups of people at different levels in different circumstances, e.g., interviewee and researcher. In addition to this, the way in which the paper is written, and the data is presented are also acknowledged to be a reflection of the primary researcher’s own social context and understanding of the world.

Co-production methodology

What is co-production

Co-production is a way of working that is being promoted across all realms of public services including the NHS and local authorities (Social Care Institute for Excellence, 2015). The Coalition for Collaborative Care provides the following definition: “Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.”. This way of working is now often a mandatory part of developing and evaluating services. For example, The Care Act (2014) recognises that "In developing and delivering preventative approaches to care and support, local authorities should ensure that individuals are not seen as passive recipients of support services but are able to design care and support based around achievement of their goals. Local authorities should actively promote participation in providing interventions that are co-produced with individuals, families, friends, carers and the community” p. 17.

Needham (2008) recognises that co-production of services in the public sector is empowering for both frontline staff and service users who are given a voice in developing services through these methods, enabling staff and service users to have a sense of agency and responsibility in service development. It is also hoped that we can better meet people's needs, when they are involved as an equal with professionals and have a reciprocal relationship to get things done (Boyle at al., 2010). Co-production consists of not just co-creating someone's care with them on an individual basis but also in developing and evaluating services on a systems level.

One element of developing and evaluating services in a co-produced way is to have co-production within research studies to enhance the quality and impact of evidence-based practice (Howard & Thomas-Hughes, 2021). Conducted in this way, research aims to create new knowledge that meets the needs, expectations, and values of modern societies broadening the impact of research in terms of social value and contribution (Grau et al., 2017). Co-production methodology therefore seeks to bring a better representation of marginalised groups into research by producing data that has a greater representation of the community's need and provides more opportunities for local involvement and empowerment (Guta et al 2013). Facer and Enright (2016) suggest that co-productive methodology seeks to bring together complementary skills, knowledge, experiences, and expertise by balancing power between universities and community-based organisations. Beebeejaun et al. (2015) suggests that co-produced research is successful when there is a commitment to hearing unheard voices and groups, whilst also being sensitive to the potential of institutional bias.

Co-production in research has developed over time and often encompasses different approaches such as Participatory Action Research (PAR), Patient and Public Involvement (PPI), and collaborative research approaches. As a result of unclear definitions of what co-production is or must include, individuals working in co-production often bring their own understandings and backgrounds into the field (Horner, 2016). However, the National Institute of Health Research (NIHR) have more recently identified 5 key principles of co-production in health research (Hickey et al., 2018, p4):

- "Sharing of power – the research is jointly owned and people work together to achieve a joint understanding
- Including all perspectives and skills – make sure the research team includes all those who can make a contribution
- Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance
- Reciprocity – everybody benefits from working together
- Building and maintaining relationships – an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential."

Whilst there is now more guidance available to suggest how co-production should look and what it should involve, it is clear there are still some challenges with co-production. Farr et al. (2021) facilitated reflective workshops with researchers who had experienced co-production and concluded that 'trying to maintain all principles of co-production within the real-world of structural inequalities and uneven distribution of resources is a constant challenge, often remaining for now in the realm of aspiration'. Dixon et al. (2019) recognise that realistic timescales, costs, and flexibility are all areas that need careful consideration when working in a co-produced way. It is with this above knowledge in mind that co-production in the current study was understood and utilised.

Co-production team in the current study

The current study utilised co-production principles throughout the design, implementation, and analysis of the study reflecting INVOLVE recommendations (Hickey et al, 2018). A collaborative approach to the research was utilised in order to transform the potential of the research to achieve meaningful change (Faulkner et al. 2019). From the outset of the project, ideas were developed with a co-production team to ensure that the scope, purpose, and development of the study were important and acceptable to those that it aimed to impact. The Green Light Champion Network (GLCN) within the mental health organisation made up the co-production team, with a smaller more focused working group of the primary researcher and volunteers who were instrumental in specific decision making and analysis. The GLCN is a collection of volunteers made up of clinicians from the mental health organisation, service users, and third-party representatives. This network of people aims to drive quality improvements by increasing the accessibility of services for all individuals across the organisation and within associated services. The network has a particular interest in learning disability and autism. Given that the research study aimed to find out more about clinicians’ experiences of working with individuals who have literacy difficulties, this network of individuals was a good fit for the purpose of the study given that co-production is about conducting research with those who will use it (Graham et al., 2019).

Co-production process

Table 5.1 provides an outline of how co-production was an integral part of every stage of the research process and the impact this had. The following part of this chapter provides further detail and reflections to illustrate the use of co-production in the current study.

Table 5.1. Co-production involvement and impact

Research stage	**Co-production involvement**	**Impact**
Identifying the research question	• Clinical lead requested research into practices with literacy in the mental health organisation • Large co-production group (50+) met to discuss aims and provide suggestions for avenues of research, opportunity to engage key stakeholders • Working group met to identify specific research questions (made up of clinicians, service users, and third-party representatives)	• There was agreement that this was an area of importance for the context in which it took place • Research aims were twofold: increase awareness of literacy within the organisation and understand clinicians’ experiences • It was decided that English as a second language was a distinct and separate construct that would require a different approach and thus a focus on literacy difficulties in the context of English as someone’s first language was agreed upon • There was an agreement that there would be mutual responsibility for the research between researcher and co-production team • ‘Let’s talk literacy’ name developed as a catchier title for the project to increase engagement
Designing interview topic guide and materials	• Working group met to discuss what topic guide needed to cover • Joint creation of topic guide	• Person-centred care became a central element of the project and topic guide included prompts asking participants to discuss how they involved individuals in their own care

Table 5.1. Co-production involvement and impact

		• A focus on how services can do better was introduced to the topic guide by use of a prompt around what organisations can do to empower service users with literacy difficulties
Data Collection	• Co-production group shared research advert and information with colleagues to promote participation	• Recruitment was promoted by the GLCN- disseminating information to their networks and clinical colleagues
Data Analysis and Coding	• Co-production group involved in all stages of analysis. • Every transcript analysed by primary researcher and at least one member of co-production group	• First transcript was analysed by all of the working group in order to agree definitions of initial codes and ideas • Initial theme framework development was a collaboration of whole working group • Themes were developed from a shared practitioner perspective with an emphasis on practice and approach • Discussing multiple viewpoints on every transcript, allowed for reflexivity in analysis by co-production group and increased validity
Verification of key messages/outputs	• Co-production group met together after all transcripts coded to decide on final themes and operational definitions for	• The five superordinate themes (intersectionality, clinician attitude, humanistic approach, service provision, and social inequality) were agreed by all members of the group

Table 5.1. Co-production involvement and impact

	each theme to reflect key messages • Co-production group reviewed thematic diagram and gave feedback	• Diagrammatic representation of the themes was altered to fit a person-centred model as opposed to initial process focused model
Dissemination	• Co-production group to be involved in video to disseminate findings	• Results of the project are jointly owned by the co-production group and shared in a way that is relatable • Dissemination of the results will reach those who it can impact most • Regular updates were presented to the GLC network at their network meetings • All of the working group will be named on final publication

In the project's initial stages, meetings with the clinical lead and wider co-production team were used to determine what was important to this group of people and what research would be beneficial to them. These initial meetings with the GLCN revealed a group of people who felt passionate that they had to fight to get their voice heard. This meant they were keen to be involved and have the opportunity of another platform through which they could work towards increased accessibility for all. This passion was vital for driving and shaping the project. With over 50 people sharing ideas and experiences at the initial meeting, it gave a voice to many, and created a sense of excitement and pride for people in what they stand for. It was helpful to be able to understand the perspectives of many and get contributions from all those who wanted to input. Through a presentation of the current literature available in this area (literacy and mental health) and the use of a question-and-answer session, the research began to take shape, co-developed as a team.

A more focused project coproduction working group was then formed to help fine-tune the ideas for the development and management of the research. This group was made up of the primary researcher and a mix of service users and clinicians, who volunteered their time. The sense of reciprocity was clear, with this working group feeling they would be able to use this research as a platform to raise awareness of literacy support, and see changes happen within the mental health organisation. Boyle and Harris (2009) recognise reciprocity as a key feature of co-production in building mutual trust and respect within working relationships. It is worth noting that this working group were self-selecting due to their shared and common interest in the subject area and may not be representative of the wider mental health workforce. However, the primary purpose of the research was to understand the dynamics of literacy needs and practices as related to person-centred care, and therefore it required people who had reflected on this particular area of their practice to drive the research process.

In line with Hickey et al. (2018), the research aimed to be jointly owned between the primary researcher (Trainee Clinical Psychologist) and the co-production group, whilst being representative of the perspectives and skills of all those that wanted to be involved. This aim had to be achieved alongside the aim of achieving a doctoral level thesis project that conformed to university academic and governing research body standards. This balance of aims and purpose for the research required objectives to be clearly decided as a joint entity at the very beginning of the conception of the project. This served as an anchor to keep coming back to throughout the project as a guiding factor when thinking about where the project was going. In order to get this balance, it was important to have good working relationships with the clinical lead for the co-production group as well as the individual members of the group.

The working group structured how the research would look as well as helping to think about the aims of the research in the context of wanting to raise awareness and create change. In doing this the group helped to define what the research question was and how it would be explored. One idea from the working group was that they felt that the research needed to have a short catchy title in order to grab people's attention. It was within this group that the shorter study title of 'Let's Talk Literacy' was developed and subsequently used throughout the project. The group created the topic guide for interview and thought about how the research could be promoted across the organisation. This commitment from the research group was vital in being able to recruit to the study as they were influential in being able to spread the word about the research. The sharing of decision-making and flexibility of the research was helpful in maintaining a balance of power and allowed for the co-researchers to shape the research based on their input and insights (King & Gilliard, 2019).

Due to implications of COVID-19 on services and individuals, combined with the research project being put on hold for a year, the original working group disbanded. Further to this, the original clinical lead who had been instrumental in getting the project running had now moved on from the service and was no longer able to support the research. It was a loss to not have this initial group to keep the project going as they had been so crucial in the development of the research and at this point the project was halfway through. However, the wider co-production group of the GLCN was still in place and so the researcher was able to go back to the network to ensure it still had the support of the wider group who had initially driven it. In doing this, a new working group was established. This working group was much smaller and perhaps this reflected the extra pressures on individuals whilst in a global pandemic.

Involvement in data analysis

The working group were particularly instrumental in the analysis of the data. Due to wanting the analysis process to be accessible for all members the initial plans to use specialist analysis software had to be changed due to availability of such programmes for those not affiliated with the university. To ensure the working group felt valued and their voices all had an equal role, analysis of the qualitative data did not start until the whole group was available. It was essential for the authenticity of the co-produced nature of the project to do this. Having a team of people for the qualitative analysis was beneficial in not just reflecting the researcher's interpretation of the data but also for capturing a wider understanding. Through video call meetings the group were able to hear the varying interpretations that the different members brought to the analysis and for discussions to evolve around these. This group analysis allowed for issues and themes to arise that may have been overlooked by the researcher, thereby increasing the validity of the research (Goodson and Phillimore, 2012).

The co-production nature of this project also appeared to serve a function in and of itself, raising awareness of the study topic. Reupert (2018) identifies that collaborative research, that engages stakeholders as a central aim from the start, can intentionally have an impact and influence within the context in which it sits. In the initial stages of project design the wider co-production group reflected on how anything would be helpful if it raised awareness of this important area. Indeed, by using co-production methodology and utilising a network of individuals across services conducting the research, this began to open up conversations around literacy awareness within different spheres. Meyer (2000) describes how research that has a participatory nature has the ability to simultaneously influence practices whilst also gathering information to share on a wider level. Even after recruitment was completed, there were still interested parties contacting the researcher to find out more about the research and offer support. Further to this, within the university of which the research was based, there has been discussions about this topic now becoming part of the teaching curriculum. This ripple effect of the research has been particularly powerful. Indeed, Greenhalgh et al. (2016) recognise that for research to have impact it needs to go beyond building the academic knowledge base to generating benefits to society.

Co-production and power

As has been touched on within this chapter, throughout this co-produced project it has been important to be continually aware of and reflect on issues of power within the research given the use of coproduction methodology. Lambert and Carr (2018) describe how clinical researchers naturally inherit power through historical and structural distributions within our system and that it is a researcher's responsibility within co-produced work to manage these processes ethically. Vincent at al. (2020) reflect on how power imbalances within co-produced work can be a result of bringing together individuals with different knowledge systems and ways of working. One way in which the researcher actively tried to manage this power balance was in being mindful about language, trying to only use language that was accessible to all involved. Groot et al. (2020) recognises that researchers who use professional or technical jargon risk excluding those who do not share in this language. An example within this study, is when discussing ideas for how best to share the findings from the research instead of using the term 'disseminate' the researcher simply used the phrase 'sharing what we found'.

Data Analysis

Thematic analysis (Braun & Clarke, 2013) was utilised within the empirical project. Specifically, analysis of the data from the qualitative interviews was informed by Gale et al. (2013). The co-production group read through the Gale et al. paper and utilised this as a basis for their interpretation of the data. Gale et al. suggest a 7-stage method for analysis, a summary of which can be found in Appendix O. Table 5.2 shows the analysis steps within the current study.

Table 5.2. Analysis steps

Stages of analysis	**Process in the current study**
Stage 1: Transcription	The interviews were transcribed verbatim by the primary researcher. Transcripts used line numbering and had adequate line spacing and large margins either side to allow for note taking and coding in the analysis process. An independent reviewer quality checked two of the transcripts.
Stage 2: Familiarisation with the interview	The co-production working group familiarised themselves with the first transcript to be reviewed.
Stage 3: Coding	During a video conference the co-production working group went through the first few initial transcripts all together, one line at a time, using the margin to note any initial comments or ideas, and provide labels to sections of text.
Stage 4: Developing a working analytical framework	After the initial transcripts were reviewed the co-production working group met all together to agree on a set of codes to use for analysing subsequent transcripts. A working analytic framework was developed to group codes together into categories and define these categories. Different colours of highlighting were used to label sections of text when themes began to emerge
Stage 5: Applying the analytical framework	Each subsequent transcript was then analysed by the primary research and at least one other member of the co-production

Table 5.2. Analysis steps

	working group. Video conferencing was used where possible. When analysis was not able to happen as a joint process analysed transcripts were sent to the primary researcher and combined to have one transcript with joint analysis shown.
Stage 6: Charting data into the framework matrix	The data from the transcripts were then charted into a table by the primary researcher. The co-production working group then met to discuss how the data could be summarised into categories.
Stage 7: Interpreting the data.	The co-production group met to map out the data, considering the characteristics of the codes and differences between data. This process allowed for connections between and within codes to be explored and the emergent superordinate and subordinate themes to be generated.

The following example in Table 5.3. shows a short extract from a transcript after joint analysis. In the left-hand column are the emergent subordinate themes, this column was filled in later in the analysis process. The right-hand column shows initial notes/thoughts and considerations that were made in the first stages of analysis. Colour coding was used in the analysis process to indicate emerging superordinate themes. Pink represents the superordinate theme of 'social inequality'; green represents the superordinate theme of 'humanistic approach', and blue represents the superordinate theme of 'clinician attitude'. Appendix N provides a framework for each superordinate theme. These frameworks demonstrate the construction of the superordinate themes, reflect how the subordinate themes map on to these themes, and the representation of themes across the transcripts. The frameworks also offer operationalised definitions of each theme as agreed by the co-production team.

Table 5.3. Example transcript showing initial notes and emerging sub-ordinate themes

Emergent themes	**Verbatim Transcript**	Initial notes and thoughts
Internalised fear Negative views of society Need a trusting relationship Need to ask about literacy Holistic assessment Perceptions of asking about literacy How we ask about literacy/awareness of literacy Being creative about how you ask/identify Extra mile? Internalised fear? Self-stigma? Need to ask?	**Interviewee**: I would suspect embarrassment is quite common and the way, I guess that people hide it, I think that that's been a media portrayal that's been a dramatic portrayal of people over the years that I think that people have felt embarrassed that if, I'm just thinking about straight forward reading and writing, or people might tell you that you need to create the environment in which people would tell you. Can you repeat the question again? **Researcher**: Why do you think people don't typically identify themselves as having literacy difficulties to clinicians? **Interviewee**: If they're not asked, its pretty key. {as simple as that} it is as simple as that. If you don't ask you wouldn't know maybe. I just thinking I think it's just a tricky subject, I think if its, if there's a context that's very specific, so say you're asking someone something about their experience of their cognitive impairment outside of a sort of formal assessment tool it might be about asking the right question, so you know, are you having any difficulties for example signing your name anywhere on cheques or whatever, or are you having any difficulties with understanding written language or written leaflets are you having difficulties reading, or reading text or following a plot in a book, all those sorts of things they're very nuanced questions and you have to ask them because I doubt that someone would actually tell you.	How would feeling embarrassed about a core part of how you understand and communicate with the world make you feel? Media partly to blame for societies negative views of literacy difficulties? Providing the right environment part of person-centred care People need to be asked the question Why is it tricky? What makes asking someone about their literacy abilities tricky? Link to other transcripts with this sub theme So would this come down to clinicians experience: i.e. to ask? These could be a person-centred way of asking specific questions to drill down to the information you need From their experience people don't tell you these sorts of things

Quality and rigour

Quality in qualitative research can largely be assessed by four broad principles: commitment and rigour; transparency and coherence; sensitivity to context; and impact and importance (Yardley, 2008). By showing awareness of the participant's setting, as clinicians interviewed in their role as clinician, sensitivity to context was demonstrated in the current study. Within the interviews the primary researcher used active listening skills to ensure the participants felt heard. Warmth and empathy were also utilised to help build rapport within the interviews. The co-production working group were reflective on how the identity of being a clinician in the context of being interviewed about how the organisation supports individuals may have also influenced the participant's responses as well as the co-production working group's interpretation of the data.

The in-depth engagement of the primary researcher and fellow co-production working group throughout the project demonstrated commitment and rigour. The primary researcher immersed themselves in the relevant literature and utilised the experiences and perceptions of the wider co-production team in the preliminary research discussions and conception. The primary researcher then engaged the participants in in-depth interviews which aimed to go beyond superficial answers to exploring the clinicians' experiences and perceptions. The in-depth analysis carried out by the co-production working group resulted in thorough analysis of all the data and themes which were supported with appropriate quotes from across the transcripts. The use of multiple people in the analysis allowed multiple perspectives to be reflected in the analysis process. Research supervision was also used throughout the project to corroborate quality and ensure rigour. One example of this is when the project moved to virtual methods of data collection, video/phone calls, the primary researcher and supervisor discussed how interviews could maintain their depth despite not being face to face.

Transparency and coherence were demonstrated throughout the project. The social constructionist epistemology in which the project was rooted is documented and justified with implications of this stance on the research process provided. The detailed documenting of the analysis process with the co-production working group aimed to provide clear evidence of how the interpretation was derived from the data. Furthermore, the primary researcher maintained a reflective stance throughout the project and utilised a reflective diary which was shared in supervision. The use of supervision from both the primary and secondary supervisor was also utilised to ensure the coherence of the research project and empirical paper.

The importance of the project can be seen in how it was able to generate new knowledge that is useful. The project itself impacted the organisations in which it originated by raising awareness of the need to be addressing literacy difficulties within mental health services. Both the organisation in which the project took place and the associated university of the primary researcher have commented on the ripple effect of the project and the need to be addressing literacy needs more comprehensively. Further to this, the results from the research have clear clinical implications within the organisation of which the research took place, especially given the current NHS context where person-centred care has been recognised as a priority.

Chapter Six

Discussion and Critical Evaluation

Discussion and Critical Evaluation

This thesis portfolio aimed to understand more about the relationship between literacy and mental health using a systematic review and a qualitative empirical research project. This discussion will present the outcomes from both the qualitative and quantitative research within the context of the wider knowledge base. It will also discuss the theoretical and psychological practice implications of the research whilst also critically appraising the research portfolio as a whole. Finally, it will present a reflective piece on the experiences of the researcher in conducting this research.

Literacy, the ability to read and write, is a basic skill required for everyday functioning within society. Globally it is estimated that there are 773 million adults across the globe that cannot read and write (UNESCO, Institute of Statistics, 2021). Within England it is estimated that 16.4% of adults in England have ‘very poor literacy skills’ (NLT, 2012). Poor literacy skills are therefore prevalent across a global and local picture. Prior research suggests that a lack of literacy skills is associated with various negative outcomes such as, higher criminal offence rates (Morrisroe, 2014), increased risk of hospitalisation (Baker et al., 2002), poorer global health status, and shorter life expectancy (Gilbert et al., 2018). The current thesis portfolio aimed to explore the putative relationship between literacy and mental health by examining prior research and interviewing mental healthcare professionals. It is important to understand what impact literacy has on mental health from different perspectives, in order to understand how psychologists and other mental healthcare professionals can support people with literacy needs to successfully engage with mental health support.

Overview of the research

Systematic review

The systematic review used a narrative synthesis of quantitative studies to provide an overview of research from the past 10 years that explored the relationship between literacy and mental health outcomes across the globe. Seventeen out of 19 papers included in the review found a significant relationship between literacy skills and mental health outcomes, poorer literacy abilities were associated with poorer mental health outcomes. The evidence in this review suggested that there may be several social inequalities acting as potential mediating factors in the relationship between literacy and mental health. Age, gender, years of schooling, and poverty all had interaction effects adding to our understanding of the impact of social determinants on mental health. This review is the first known attempt to systematically examine prior quantitative research measuring literacy levels and mental health outcomes, and supports the hypothesis that there is a relationship between the two factors.

Empirical research project

The empirical research project used co-production methodology to explore the relationship between literacy and mental health within UK clinical practice. This was the first known qualitative study to have explored mental health clinicians' experiences of working with individuals in NHS mental health services who had literacy difficulties. This research provides an in-depth account of clinician's views on how literacy difficulties might impact on delivering person-centred care, the improvement of which is one of the aims of the NHS Long Term Plan (2019). Nine members of staff from different professional training backgrounds were interviewed in order to understand more about how professionals perceive the relationship between literacy and mental health in practice settings, but also how complexity of presentation and needs relating to both factors might impact on someone's journey and experiences through mental health services. The outcomes highlighted potential barriers to person-centred care as well as facilitators of empowerment for those with both literacy and mental health difficulties. Five overall themes that resonated with the co-production team were identified within the participants' experiences: Intersectionality; Clinician Attitude; Humanistic Approach; Service provision; and Social inequality.

These themes describe how participants felt that mental health and literacy were interdependent, with both factors having a synergistic impact on people's presenting difficulties. Participating clinicians spoke about how they felt that a humanistic approach was crucial for enabling person-centred care where there were layers of complexity. Participants also felt that a therapeutic relationship was crucial in developing trust with service users in order for them to feel able to be open about their literacy difficulties.

Participants described how their experiences led them to believe that organisations often assume adequate literacy skills and that consequently they may risk disempowering individuals and having potentially significant impacts on engagement. This assumption of literacy was viewed in the context of a social inequality for those with literacy and mental health difficulties. Participants reflected on how they felt that society views those with a lack of literacy negatively, and that societal and internal stigmas may create barriers for people with low literacy to achieve their goals in life. Clinicians perceived that some staff might find it difficult to talk to service users about their literacy difficulties due to these stigmas, but it was important to go the extra mile to meet the needs of individuals through support and advocacy. These stigmas were also hypothesised as contributing to individuals masking or hiding their difficulties with literacy.

Theoretical Implications

Together the systematic review and empirical paper use quantitative and qualitative data to suggest that there is a relationship between literacy and mental health. The systematic review largely used cross sectional data to reflect this relationship and thus causality or direction of this relationship is difficult to infer. However, the empirical research project explores this further by asking clinicians to reflect on their beliefs around the nature of this relationship. In this exploration clinicians provide their personal perspectives around how literacy difficulties might contribute to mental health difficulties through various factors including isolation, poor self-esteem, low self-worth, and internalised stigma. They also discussed how they perceived mental health difficulties, particularly times of mental health crisis or neurodegenerative conditions supported in mental health services, can impact on the cognitive skills required for adequate literacy.

Within the systematic review several potential mediating factors in the relationship of literacy and mental health were highlighted; age, gender, years of schooling, and poverty level. It is important to recognise that all of these mediating factors represent social inequalities and have been identified as social determinants of mental health (WHO, 2014). Social determinants reflect the social, economic, and physical inequalities that are associated with higher risk of poorer mental health outcomes. The results from the systematic review suggest that literacy itself could represent a social determinant of mental health and this needs further exploration. Furthermore, in the empirical research project, one of the findings was to suggest that the stigma associated with low literacy might act as a potential contributing factor impacting on mental health. Hatzenbuehler et al. (2013) conceptualise stigma as a social determinant of both physical and mental health. The model of social determinants of mental health described in WHO (2014) highlights the role the wider society and systems play within social inequalities. Compton and Shim (2015) propose that social contextual factors, social norms, and public policies which are mutually reinforcing, are drivers for unequal distribution of opportunity and thus social determinants of mental health. Therefore, findings from both the empirical research project and the systematic review support the conceptualisation of literacy as a social determinant of mental health, where stigma experienced in society and systems, contributes to the perpetuation of inequalities in mental health.

Participants in the empirical research project perceived stigma to have a significant role in the experiences of an individual with both mental health and literacy difficulties. Dudley (2000) defines stigma as negative attributions given to a person or group when they are viewed as inferior to, or different to, social norms. There is substantial literature documenting the stigma related to mental health and the implications of this (Corrigan & Bink, 2016), including how stigma negatively impacts on help-seeking (Clement et al., 2015). However, literacy-related stigmas have so far been less widely explored. Within the empirical research project clinicians described stigma related to the negative attributions given to those who have difficulties with literacy, as in society this is viewed as different to the norm of being literate. Ahmedani (2011) describes 3 levels of stigma: social stigma, self-stigma, and professional stigma. Clinicians in the empirical project particularly reflected on the social stigma and self-stigma associated with literacy difficulties. They expressed beliefs about perceived structural inequalities in society that create barriers for those with literacy difficulties. In line with Ahmedani’s description of social and self-stigma they identified how literacy related stigma results in inequalities in access to treatment services and then the processes by which this social/public stigma is internalised. Participants in the empirical project believed that stigma within society may be reflected in the way organisations are designed, creating significant gaps for those that are unable to read or/and write. They also expressed beliefs around how this perceived stigma within services and internalised stigma from experiences within society might lead an individual to mask or hide their difficulties.

The findings from clinicians around the role of stigma in the association between literacy and mental health described in the empirical paper are supported by previous research with individuals who have literacy difficulties. Easton et al. (2013) interviewed adults with low literacy and found that stigma associated with literacy difficulties impacted on mental wellbeing due to the impact it had on an individual’s experiences of social isolation and ongoing anxiety around revealing their difficulties with literacy. Furthermore, Easton et al. found that this stigma associated with low literacy impacted on individual's interactions with healthcare professionals and their engagement with healthcare provisions, which was mirrored in the empirical research project. Prior literature also suggests that social stigma is a predictor of engagement with treatment plans for those with low literacy (Waite et al. 2008). Accordingly, clinicians in the empirical research project explored their beliefs around how social stigmas being reinforced by structural inequalities in mental health services have the potential to significantly impact on service user engagement. Thus, the empirical research project utilises the experiences and beliefs of mental health clinicians to expand on previous literature, to understand more about the role of stigma within this complex interplay of both literacy and mental health difficulties.

Clinical Implications

Given the association that this portfolio has found between literacy and mental health it is important for services and systems to consider promoting literacy from an early age, and across the lifespan, in order to proactively have a positive impact on mental health outcomes. Okan and WHO (2019) recognise the importance of early childhood in addressing health inequalities through tackling health literacy. Literacy is a core-component required for health literacy, therefore, in order to improve overall health equality literacy levels need to be improved. Baker- Henningham (2014) argued that early childhood education programmes need to be incorporated into the global mental health agenda as a preventative initiative for future mental health. Adult literacy programmes have also been found to have numerous benefits including a positive impact on wellbeing and psychosocial outcomes (Dolan et al., 2012; Prins, 2008). The evidence from this portfolio would argue that literacy skills should be included in this agenda as a key priority.

The research presented in the papers together also highlight the importance of healthcare professionals being able to identify and support people with literacy difficulties within mental health practice settings. In order to be able to identify individuals with literacy difficulties clinicians need to have an awareness of how to identify literacy difficulties. The participants in the empirical project suggested that they believed that not all staff are aware of literacy difficulties or feel comfortable in asking people about their literacy needs, perhaps linked to the wider systemic inequality and social stigmas described by participants. Therefore, services need to be offering support, perhaps in the form of formal training and supervision, to staff to empower them with both knowledge and confidence to be able to adequately identify and support literacy needs. Ultimately the intention of this approach will be to support service users to make informed health decisions while building trust and therapeutic relationships between individuals and services, in line with the principles of person-centred care set out in the NHS Long Term Plan.

Given the association found in this portfolio between literacy and mental health it is important to consider the clinical implications for treatment. Many psychological treatments for mental health difficulties rely heavily on literacy skills, for example CBT often utilises workbooks and homework as core components (Dozois, 2010). In order for treatment options to be accessible for individuals with literacy difficulties, adaptations to usual treatment protocols are likely to be required. Kuhajda et al. (2011) recognise that adequate attention has not been given to appropriate adaptations of psychosocial treatment options. Thorn et al. (2011) adapted a group CBT programme for a low-literacy population. Whilst their adapted intervention was found to be acceptable to participants, they suggested that their high drop-out rates could be indicative of further adaptations required, specifically to account for cognitive load. Campbell (2011) suggests that one way to adapt interventions to be more suitable for low literacy populations could be to play to an individual’s strengths by focusing on behavioural targets as opposed to cognitive targets. It has also been suggested that visual aids may be of benefit to those with low literacy (Mbanda eta l., 2021). Given the proposed role that stigma plays within the association between literacy and mental health, therapeutic interventions may also benefit from accounting for this in their approach. Livingston et al. (2011) suggest that different interventions can work at different levels of stigma; social, self and organisational. Specifically, they recognise the benefits of Acceptance and Commitment Therapy (ACT) at reducing self-stigma which is supported by Luoma and Platt (2015).

Critical appraisal of the research

There is a wealth of research suggesting an association between poorer literacy and negative physical health and social outcomes, however the relationship with mental health has received less attention. The original research and novel review of the relevant literature presented within this portfolio looking at the association between literacy and mental health outcomes addresses a gap in the literature which will be able to inform both theoretical and clinical practice. The portfolio utilised a complementary mix of quantitative and qualitative data (Sofaer, 1999). This allowed for the portfolio to identify patterns of an association on a generalisable level whilst also gaining an in-depth understanding into the phenomena from the clinicians' perspective. One of the main aims of the empirical research project was to create change within the organisation in which it took place and thus a qualitative approach was able to give this a context-specific insight. A further complementary element of this portfolio is the use of both global and local research settings. The systematic review used data from across the world to establish a global picture of literacy and mental health whilst the empirical research project further explored this association using local clinicians currently in practice.

In order to complete this link from the global context to more local experiences of clinicians, it would have been beneficial to have been able to include quantitative research to show the relationship between literacy and mental health within the local context. In the initial planning stages of the project the aim was for the research and development team, within the mental health organisation in which the empirical research project was conducted, to complete a survey to gain a picture of the prevalence of literacy difficulties within the organisation as a whole. This would have complimented the work within this portfolio well. However, due to the current context of this research being carried out within a global pandemic and resultant pressures within clinical teams, the research priorities within the mental health organisation had to adapt appropriately and therefore this was no longer a priority during the time period of the thesis.

Further to this, it is also important to acknowledge that the voice of those living with literacy difficulties and their families/carers is missing. Due to the time constraints of this portfolio, it was not possible to explore how those with literacy difficulties, and those who support them, experience mental health services. However, it is essential that future research aims to add to the literature by capturing these viewpoints. Exploring the experiences of those with literacy difficulties would enable us to know about interactions between services users, clinicians, and organisations from the other side, further building on our understanding of how wider societal issues impact on these social constructions. This knowledge of how those with lived experiences perceive things would also enable better person-centred care. It would also have been useful to explore other areas of the mental health care pathway. The clinician participants within the empirical project represented community and inpatient mental health services. However, understanding the experiences of those at the ‘front door’ of mental health services in primary and third-sector care settings, would be crucial for having a fuller picture of professional attitudes and experiences at different stages within the mental health care pathway.

When critically appraising the research in this portfolio it is important to consider its relevance to current policies and practices. The NHS Long Term Plan (2019) outlines a need to reduce health inequalities and recognises the need for a fundamental shift towards more person-centred care. The systematic review adds to our understanding of the social determinants of mental health and the role of literacy within this whilst the empirical research project directly addresses how literacy difficulties might impact on the delivery of person-centred care within mental health settings. Secondly, the NHS Long Term Plan details how services should be empowering all people to make informed health decisions through accessible health information standards. Therefore, the findings from this portfolio will be helpful in addressing the current goals of the NHS.

One of the main strengths of the empirical research project was the co-production methodology utilised. From conception to completion the co-production group was central to the progression of the study and helped to maintain its relevance within clinical settings. The co-production group, made up of clinicians, service users, and third-party representatives, acted as an anchor for the project to remain strong to its aims of creating a piece of research that would create relevant and meaningful outcomes, whilst also enhancing the research quality and impact within services (Howard & Thomas-Hughes, 2021). In engaging this network of diverse people it allowed the research project to also have a greater impact beyond the study outcomes. It raised the awareness within the organisation of literacy difficulties and allowed conversations around how literacy may impact on care to happen both within the organisation in which it took place, as well as within the university course from which the project originated. It is also recognised that by having clinicians involved in the analysis of the data, the themes and ideas that were generated from the transcripts would have been representative of the clinician participants and the clinician researchers. Thus, a shared understanding of the phenomena being explored was created.

Quality of the research in this portfolio was of upmost importance. In order to support transparency and avoid potential duplication (Stewart et al., 2012) the systematic review protocol was registered with PROSPERO (CRD42021254815), an international prospective register of systematic reviews. Further to this within the systematic review process for screening papers a second reviewer was used, this helped ensure a robust selection process (Charrois, 2015; Moher et al., 2009). The papers included in the review were rated for quality and quality scorings were provided within the review. Quality rating checks were also carried out by the second author and kappa values provided to show the level of agreement. There was variability in the quality ratings of the included studies but there was transparency around this in the paper. The heterogeneity in the systematic review of the measures used to identify mental health outcomes and literacy abilities meant that a meta-analysis was not possible. Therefore, whilst descriptive statistics and a narrative synthesis establish that an association between literacy and mental health is likely it does not provide us with a measure of the extent of this relationship.

Within the empirical research project the co-production working group were central to the analysis, this allowed for investigator triangulation. This is where multiple researchers are involved in addressing the organisational elements of the study as well as the analysis to ensure credibility of qualitative research (Kasirye, 2021). In the initial conception of the project, the aim was also to use respondent validation to ensure that the themes identified from the analysis were accurate and resonated with their experiences. Noble and Smith (2015) identify that doing this can improve the reliability and validity of research allowing for verification of the themes being an adequate reflection of the phenomena being investigated. However, due to the time restrictions on the project in the context of it being completed as part of a doctorate in clinical psychology this was not possible.

It is also important to consider the epistemology of the researcher in their position within this portfolio, particularly within the empirical research project given its qualitative methodology. The researcher has approached this portfolio from a social constructionist position as described in the additional methods chapter. In taking this stance the researcher looks beyond a focus on the individual, to society and interactions that form language. Given this thesis was looking at individuals with specific difficulties and their experiences within systems, whilst also bringing in relevant stigma literature, this approach was considered appropriate given how social constructionism is interested in ‘normative narratives’ which are created in and in turn influence individuals and how they measure themselves against such narratives (Van Niekerk, 2005). Indeed, within the empirical research project the participants drew on their professional identities and reflected on themselves in a social world, for example distancing themselves from the stigmatising narratives in society. The way in which participants identified within the research was fitting within a social constructionist framework. However, despite the relevance of this epistemological stance it is recognised that the researcher also brings their own interpretation to the evidence and likely has influence on the findings (Holmes, 2020). In order to minimise their own influence on the research the researcher was reflexive throughout and considered the impact of their own position within the research (Haynes, 2012).

A further consideration in the critique of this portfolio is the potential impact of the COVID-19 pandemic. This project began in 2019 and data collection started in February 2020, when COVID-19 was not yet in the awareness of most individuals and had little impact on research activities. Thus, the first 4 interviews took place face to face. In March 2020 as the NHS began to see the impact of the pandemic all NHS research that was not directly relevant to COVID-19 was put on hold this meant that the plan for all recruitment to be completed before May 2020, when the researcher went on maternity leave, was not possible.

Recruitment then re-commenced in May 2021 and all remaining participants had virtual interviews. Within this time, the pandemic continued, leading to changed and sustained pressures and priorities on clinicians working in mental health services (Gemine et al. 2021). Given the social constructionist approach in the empirical paper it is therefore worth considering how the pre and post COVID-19 interviews may differ given that language and society plays an interactive role in how we understand ourselves and the world around us (Galbin, 2014).

Future research

In order for future research to be able to draw more meaningful conclusions about the relationship between literacy and mental health, a tool that specifically measures literacy, as a separate construct from years of schooling, should be developed and utilised within research. Developing and validating a global standardised specific measure of literacy would enable the research field to be more specific about the relationship between literacy and mental health. A more consistent approach to measuring literacy would also allow for more robust reviews of the evidence including a meta-analysis which could look at the extent of the relationship between literacy and mental health outcomes. A specific measure of literacy would also allow further exploration of literacy as a social determinant of mental health. Education is an established social inequality linked to poorer physical and mental health outcomes (Compton & Shim, 2015). Whilst the current research suggests that literacy may by a separate and distinct social determinant of mental health without a specific and standardised measure of literacy these claims remain tentative.

Whilst this portfolio presents the global evidence for a relationship between literacy and mental health and then uses UK clinicians to understand more about this relationship, it is missing the experiences of those with literacy difficulties in mental health services. It is important for future research to give a voice to those with literacy needs in mental health services. It is vital, as suggested by some participating clinicians in the empirical research project, that services make better use of those with lived experiences of literacy difficulties to ensure that services are designed in a non-stigmatising way. Future research, utilising those with lived experience, could look to co-develop and trial a training and awareness package around literacy difficulties for health and social care staff. Given the findings in this current portfolio, it would be useful to evaluate the effect of implementing training packages around literacy on the empowerment of both clinicians providing care and recipients of care.

The NHS Long Term Plan (2019) sets out integrated care systems (ICS) as part of its future direction. ICS are partnerships between NHS services and local authorities and other partners within a geographically area to deliver care (Kings Fund, 2021). Given that the aim of this shift towards ICS is to aid greater integration of health and care services it would be useful to explore this association of literacy and mental health, and its impact on an individual's journey through services, fully across the whole of the ICS.

Personal reflections

In beginning this portfolio of research, I was somewhat anxious and excited to embark on the biggest piece of research I had conducted to date as well as to be the primary researcher and have that level of responsibility within the project. I have learnt a lot about the process of research as well as myself throughout this project. I have learnt about the skills that lend themselves well to research, such as organisation, time management, and good communication skills as well as the skills that will continue to be developed through supervision and guidance from both research peers and supervisors. I have also changed personally over the course of this project and had a maternity year within the time in which this project has been completed. This has also been in the context of a global pandemic which will also have shaped and impacted on how I work both clinically and within my research. I believe that this significant life change, and global issue, has also impacted on the way that I see and appreciate the world, as well as how I prioritise my time. In particular, being on maternity leave during a national lockdown gave me an appreciation for the importance of personal connection. When returning to work, and the empirical project, hearing clinicians describe in interviews how important relationships were and connecting with others really resonated with me. Given that my empirical project was qualitative in nature I have found it helpful on a personal level to reflect on how these life experiences may have impacted on this research portfolio as a whole. The process of this research, particularly the empirical project, has shaped my identity as a professional. Given that the empirical project was exploring a dynamic in a context in which I am currently, and will continue to be working in, I feel I will now have a greater awareness of literacy difficulties in my future practice. With this increased awareness I now feel more empowered to ask people about their literacy needs as part of my routine practice and how I might support those with literacy needs through appropriate person-centred care.

My experience of co-production has been a very positive experience that I hope to take forward into both my clinical and research roles. At times it has felt overwhelming trying to co-ordinate different individuals with different experiences and contributions whilst also holding in mind my university research requirements, ethics, and protocols. However, the people I have had the chance to meet and the voices I have had a chance to listen to will shape my professional career indefinitely. The motivation and enthusiasm of clinicians and service users whose passion sits within this field has been remarkable. Their dedication and insights have provided me with my own motivation to create authentic research that can create change in this area. It has shown me the power of not just leading in my own direction but in stepping back and listening to others and collaboratively taking action. I know that my experience of co-production within this research project will continue to impact my future thinking both within my clinical and research paths. I will now be more aware of the positive role of co-production whilst also being more aware of some of the challenges and how to over-come these, particularly in managing balances of power. Going into qualified life, acting as an autonomous practitioner, I will seek to draw on and promote co-production when considering service development and evaluation.

My reflections following co-production meetings left me realising how important it was to have the input and support of this co-production group in order to make the research feel meaningful for the organisation in which it was happening. Turnhout et al. (2019) recognise that scientific expertise is not enough in itself, but that stakeholder knowledge is vital for co-production to be socially robust and this was a strong driving factor within this research. The sense of wanting to create something that would have a direct clinical impact for those involved in the project was key to me as a motivator throughout the empirical research project. The passion of the other members of the working group also felt contagious and knowing what was important to the various stakeholders was vital to the project developing and moving forward as a coproduced research project. By working in this way, I aimed to increase the authenticity by capturing the lived experience of the community members (Devotta et al. 2016). The support of this co-production group was very motivational as a researcher and made me committed to publish the research to honour everyone who has contributed along the way, thereby increasing my feeling of responsibility and accountability to the importance of this research project.

As a researcher the process of designing research alongside a team of people without research backgrounds and experience was also one that was at times challenging. Boyle et al. (2010) recognise some of the challenges that co-production can pose and how at times it can feel quite ‘messy’ and requires particular skills to be a co-production practitioner. It also felt a large task to balance the co-production with the research protocols and deadlines which at times could feel quite frustrating. On a practical level, trying to find a time to get everyone together to meet and discuss the research in a way that was inclusive to all of the members of the group was at times a logistical difficulty. There were also challenges in conveying the importance of procedures around research, such as ethical approval processes and the paperwork included in research which was a new concept for many in the group. These challenges meant that keeping a reflective diary as the primary researcher was particularly helpful for managing the different challenges as well as having the space to reflect on the most helpful way for moving forward. Thomas-Hughes (2018) argues that methodological learning comes from reflecting on co-production's 'messy places' such as struggles with power, partnership, and ethics.

Conclusions

This portfolio has looked at the association between literacy skills and mental health. The results suggest that on a global level there appears to be an association between literacy difficulties and poorer mental health outcomes and that various social determinants may mediate this relationship. In depth exploration of this relationship within a specific context found that clinicians reported that this intersectionality of literacy and mental health impacts on how person-centred care is delivered to this population. Participants drew on their experiences and beliefs around how stigma plays a significant role within individuals' interactions with mental health services when they have literacy difficulties. The research presented here suggests the importance of support across the lifespan of literacy skills as a preventative measure for mental health. It also demonstrates how crucial it is that services and clinicians are aware of literacy difficulties and how to best support them. Further research is required to be able to ascertain the extent of the relationship between literacy and mental health and understand more about the mediating factors in this relationship. It is also imperative that future research captures the voice of those with lived experience of both literacy and mental health difficulties in order gain an in-depth understanding of their experiences to shape services moving forward.

Thesis Portfolio References

Ahmedani, B. (2011). Mental health stigma: society, individuals, and the profession. *Journal of social work values and ethics, 8*(2), 4-1.

Baker, D. W., Gazmararian, J. A., Williams, M. V., Scott, T., Parker, R. M., Green, D., ... & Peel, J. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American journal of public health, 92*(8), 1278-1283. https://doi.org/10.2105/ajph.92.8.1278

Baker-Henningham, H. (2014). The role of early childhood education programmes in the promotion of child and adolescent mental health in low-and middle-income countries. *International journal of epidemiology*, *43*(2), 407-433. https://doi.org/10.1093/ije/dyt226

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. Anchor.

Beebeejaun, Y., Durose, C., Rees, J., Richardson, J., & Richardson, L. (2015). Public harm or public value? Towards coproduction in research with communities. *Environment and Planning C: Government and Policy*, *33*(3), 552-565. https://doi.org/10.1068%2Fc12116

Boyle, D., & Harris, M. (2009). *The challenge of co-production*. New Economics Foundation. https://neweconomics.org/uploads/files/312ac8ce93a00d5973_3im6i6t0e.pdf

Boyle, D., Coote, A., Sherwood, C., & Slay, J. (2010*). Right here, right now. Taking co-production into the mainstream.* National Endowment for Science, Technology and the Arts. https://media.nesta.org.uk/documents/right_here_right_now.pdf

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

Burr, V., & Dick, P. (2017). *Social constructionism. In The Palgrave handbook of critical social psychology*. Palgrave Macmillan.

Campbell, L. C. (2011). Addressing literacy as a barrier in delivery and evaluation of cognitive-behavioral therapy for pain management. *Pain, 152*(12), 2679-2680. https://doi.org/10.1016/j.pain.2011.09.004

Care Act. (2014). HM Government. https://www.legislation.gov.uk/ukpga/2014/23/contents

Charrois, T. L. (2015). Systematic reviews: what do you need to know to get started?. *The Canadian journal of hospital pharmacy*, *68*(2), 144. https://dx.doi.org/10.4212%2Fcjhp.v68i2.1440

Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., ... & Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological medicine, 45*(1), 11-27. https://doi.org/10.1017/s0033291714000129

Compton, M. T., & Shim, R. S. (2015). The social determinants of mental health. *Focus, 13*(4), 419-425. https://doi.org/10.1176/appi.focus.20150017

Corrigan, P., & Bink, A. B. (2005). *On the stigma of mental illness*. American Psychological Association.

Cree, A., Kay, A., & Steward, J. (2012). *The economic and social cost of illiteracy: A snapshot of illiteracy in a global context*. World Literacy Foundation.

Department for Business Innovation & Skills. (2015). *International Evidence Review of Basic Skills survey in 2015 (209).* http://www.nrdc.org.uk/wp-content/uploads/2015/11/bis-15-33-international-review-of-adult-basic-skills-learning-from-high-performing-and-improving-countries.pdf.

Devotta, K., Woodhall-Melnik, J., Pedersen, C., Wendaferew, A., Dowbor, T. P., Guilcher, S. J., ... & Matheson, F. I. (2016). Enriching qualitative research by engaging peer interviewers: A case study. *Qualitative research, 16*(6), 661-680. https://doi.org/10.1177%2F1468794115626244

Dixon, J., Ward, J., & Blower, S. (2019). “They sat and actually listened to what we think about the care system”: the use of participation, consultation, peer research and co-production to raise the voices of young people in and leaving care in England. *Child Care in Practice, 25*(1), 6-21. https://doi.org/10.1080/13575279.2018.1521380

Dolan, P., Fujiwara, D., & Metcalfe, R. (2012). Review and update of research into the wider benefits of adult learning (90). Department for Business Innovation & Skills. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/34671/12-1243-review-wider-benefits-of-adult-learning.pdf.

Dozois, D. J. (2010). Understanding and enhancing the effects of homework in cognitive-behavioral therapy. *Clinical Psychology: Science and Practice, 17*(2), 157-161. https://psycnet.apa.org/doi/10.1111/j.1468-2850.2010.01205.x

Dudley, J. R. (2000). Confronting stigma within the services system. *Social Work, 45*(5), 449. https://doi.org/10.1093/sw/45.5.449

Easton, P., Entwistle, V. A., & Williams, B. (2013). How the stigma of low literacy can impair patient-professional spoken interactions and affect health: insights from a qualitative investigation. *BMC health services research, 13*(1), 1-12. https://doi.org/10.1186/1472-6963-13-319

Facer, K., & Enright, B. (2016). *Creating Living Knowledge: The Connected Communities Programme, community-university partnerships and the participatory turn in the production of knowledge.* Arts and Humanities Research Council. https://connected-communities.org/index.php/creating-living-knowledge-report/.

Farr, M., Davies, P., Andrews, H., Bagnall, D., Brangan, E., & Davies, R. (2021). Co-producing knowledge in health and social care research: reflections on the challenges and ways to enable more equal relationships. *Humanities and Social Sciences Communications, 8*(1), 1-7.

Faulkner, A., Carr, S., Gould, D., Khisa, C., Hafford-Letchfield, T., Cohen, R., ... & Holley, J. (2021). ‘Dignity and respect’: An example of service user leadership and co-production in mental health research. *Health Expectations, 24*, 10-19. https://doi.org/10.1111/hex.12963

Filipe, A., Renedo, A., & Marston, C. (2017). The co-production of what? Knowledge, values, and social relations in health care. *PLoS biology, 15*(5), e2001403. https://doi.org/10.1371/journal.pbio.2001403

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology, 13(*1), 1-8. https://doi.org/10.1186/1471-2288-13-117

Galbin, A. (2014). An introduction to social constructionism. *Social Research Reports*, 6(26), 82-92.

Gemine, R., Davies, G. R., Tarrant, S., Davies, R. M., James, M., & Lewis, K. (2021). Factors associated with work-related burnout in NHS staff during COVID-19: a cross-sectional mixed methods study. *BMJ open, 11*(1), e042591. https://doi.org/10.1136/bmjopen-2020-042591

Gergen, K. (2004). Constructionism, Social. *The SAGE Encyclopedia Of Social Science Research Methods. 1*, 183-185. http://dx.doi.org/10.4135/9781412950589.n164

Gilbert, L., Teravainen, A., Clark, C., & Shaw. (2018). *Literacy and life expectancy and socioeconomic factors*, National Literacy Trust. http://cdn-literacytrust-production.s3.amazonaws.com/media/documents/National_Literacy_Trust_-_Literacy_and_life_expectancy_report.pdf.

Gillard, S., Turner, K., Lovell, K., Norton, K., Clarke, T., Addicott, R., ... & Ferlie, E. (2010). “Staying native”: coproduction in mental health services research. *International Journal of Public Sector Management, 23*(6), *567-577. http://dx.doi.org/10.1108/09513551011069031*

Goldberg, D. S. (2017). On stigma & health. *Journal of Law, Medicine & Ethics, 45*(4), 475-483. https://doi.org/10.1177/1073110517750581

Goodson, L., & Phillimore, J. (2012). *Community research: Opportunities and challenges. Community research for participation: From theory to method*. Policy Press.

Graham, I. D., McCutcheon, C., & Kothari, A. (2019). Exploring the frontiers of research co-production: the Integrated Knowledge Translation Research Network concept papers. *Health Research Policy and Systems*. https://doi.org/10.1186/s12961-019-0501-7

Grau, F. X., Goddard, J., Hall, B., Hazelkorn, E., & Tandon, R. (2017). *Higher Education in the World 6: Towards a socially responsible university: Balancing the global with the local*. Global University Network for Innovation.

Greenhalgh, T., Raftery, J., Hanney, S., & Glover, M. (2016). Research impact: a narrative review. *BMC medicine, 14*(1), 1-16. https://doi.org/10.1186/s12916-016-0620-8

Groot, B., Haveman, A., & Abma, T. (2020). Relational, ethically sound co-production in mental health care research: epistemic injustice and the need for an ethics of care. *Critical Public Health,* 1-11. https://doi.org/10.1080/09581596.2020.1770694

Guta, A., Flicker, S., & Roche, B. (2013). Governing through community allegiance: a qualitative examination of peer research in community-based participatory research. *Critical public health, 23*(4), 432-451. https://dx.doi.org/10.1080%2F09581596.2012.761675

Harper, D. (2011). *Choosing a qualitative research method.* Wiley Blackwell.

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American journal of public health, 103*(5), 813-821. https://doi.org/10.2105/ajph.2012.301069

Haynes, K. (2012). Reflexivity in qualitative research. *Qualitative organizational research: Core methods and current challenges* (pp.72-89). Sage

Health and Social Care Act. (2012). HM Government. https://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

Heijmans, M., Uiters, E., Rose, T., Hofstede, J., Devillé, W., van der Heide, I., ... & Rademakers, J. (2015). *Study on sound evidence for a better understanding of health literacy in the European Union*. European Commission.

Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., Tembo, D., Torok, K., and Turner, K. (2018). *Guidance on co-producing a research project*. INVOLVE

Holmes, A. G. D. (2020). Researcher Positionality-A Consideration of Its Influence and Place in Qualitative Research-A New Researcher Guide. *Shanlax International Journal of Education, 8*(4), 1-10. https://doi.org/10.34293/education.v8i4.3232

Horner, L. K. (2016). *Co-constructing research: A critical literature review*. Arts and Humanities Research Council AHRC.

Howard, M., & Thomas-Hughes, H. (2021). Conceptualising quality in co-produced research. *Qualitative Research, 21*(5), 788-805. https://doi.org/10.1177%2F1468794120919092

Ishikawa, H., Hashimoto, H., & Kiuchi, T. (2013). The evolving concept of "patient-centeredness" in patient–physician communication research. *Social Science & Medicine, 96*, 147-153. https://doi.org/10.1016/j.socscimed.2013.07.026

Jankowski, P. J., Clark, W. M., & Ivey, D. C. (2000). Fusing horizons: Exploring qualitative research and psychotherapeutic applications of social constructionism. *Contemporary family therapy, 22*(2), 241-250. https://doi.org/10.1023/A:1007738021412

Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). “Mental health literacy”: a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Medical journal of Australia*, *166*(4), 182-186.

Kasirye, F. (2021). A conceptual paper on ensuring quality in qualitative research

Kesmodel, U. S. (2018). Cross-sectional studies–what are they good for?. *Acta obstetricia et gynecologica Scandinavica*, *97*(4), 388-393. https://doi.org/10.1111/aogs.13331

King, C., & Gillard, S. (2019). Bringing together coproduction and community participatory research approaches: Using first person reflective narrative to explore coproduction and community involvement in mental health research. *Health Expectations, 22*(4), 701-708. http://dx.doi.org/10.1111/hex.12908

Kings Fund. (2021). *Integrated care systems explained: making sense of systems, places and neighbourhoods*. https://www.kingsfund.org.uk/publications/integrated-care-systems-explained

Kuhajda, M. C., Thorn, B. E., Gaskins, S. W., Day, M. A., & Cabbil, C. M. (2011). Literacy and cultural adaptations for cognitive behavioral therapy in a rural pain population. *Translational behavioral medicine, 1(*2), 216-223. https://doi.org/10.1007/s13142-011-0026-2

Lal, B. S. (2015). The economic and social cost of illiteracy: An overview. *International Journal of Advance Research and Innovative Ideas in Education*, *1*(5), 663-670.

Lambert, N., & Carr, S. (2018). ‘Outside the Original Remit’: Co-production in UK mental health research, lessons from the field. *International Journal of Mental Health Nursing, 27*(4), 1273-1281. https://doi.org/10.1111/inm.12499

Lester, J. N., & O'Reilly, M. (2021). The social construction of stigma: Utilizing discursive psychology for advancing the conceptualization of stigma in mental health. *Stigma and Health, 6*(1), 53–61. https://psycnet.apa.org/doi/10.1037/sah0000281

Levy, R., Little, S., Clough, P., Nutbrown, C., Bishop, J., Lamb, T., & Yamada-Rice, D. (2014). *Attitudes to Reading and Writing and their links with Social Mobility 1914-2014: An evidence review*. Booktrust.

Lindgren, M., & Packendorff, J. (2009). Social constructionism and entrepreneurship: Basic assumptions and consequences for theory and research. *International Journal of Entrepreneurial Behavior & Research*, *15*(1), 25-47. http://dx.doi.org/10.1108/13552550910934440

Literacy Trust (2012). *Adult Literacy Statistics*. (https://literacytrust.org.uk/parents-and-families/adult-literacy/)

Livingston, J. D., Milne, T., Fang, M. L., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: a systematic review. *Addiction*, *107*(1), 39-50. https://doi.org/10.1111/j.1360-0443.2011.03601.x

Losantos, M., Montoya, T., Exeni, S., Santa Cruz, M., & Loots, G. (2016). Applying social constructionist epistemology to research in psychology. *International Journal of Collaborative Practice*, *6*(1), 29-42.

Luoma, J. B., & Platt, M. G. (2015). Shame, self-criticism, self-stigma, and compassion in acceptance and commitment therapy. *Current opinion in Psychology*, *2*, 97-101. http://dx.doi.org/10.1016/j.copsyc.2014.12.016

McGuire, R. (2022). *Promoting children's literacy in a digitalised world.* Cache Alumni. *https://cachealumni.org.uk/CACHE/Professional-Development/Articles-folder/Promoting_children%E2%80%99s_literacy_in_a_digitalised_world.aspx#:~:text=As%20a%20child%20they%20won*

Meyer, J. (2000). Using qualitative methods in health related action research. *Bmj, 320*(7228), 178-181. https://doi.org/10.1136/bmj.320.7228.178

Mbanda, N., Dada, S., Bastable, K., & Ingalill, G. B. (2021). A scoping review of the use of visual aids in health education materials for persons with low-literacy levels. *Patient Education and Counseling, 104*(5), 998-1017. http://dx.doi.org/10.1016/j.pec.2020.11.034

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine, 6*(7), e1000097. https://doi.org/10.1371/journal.pmed.1000097

Morrisroe, J. (2014). *Literacy Changes Lives 2014: A New Perspective on Health, Employment and Crime.* National Literacy Trust.

Needham, C. (2008). Realising the potential of co-production: negotiating improvements in public services. *Social policy and society, 7*(2), 221-231.

NHS. (2019). *The NHS Long Term Plan.* https://www.longtermplan.nhs.uk/

Okan, O., & World Health Organization. (2019). The importance of early childhood in addressing equity and health literacy development in the life-course. *Public Health Panorama, 5*(2), 170-176.

Parton, N. (2003). Rethinking professional practice: The contributions of social constructionism and the feminist 'ethics of care'. *British journal of social work, 33*(1), 1-16. https://doi.org/10.1093/bjsw/33.1.1

Prins, E. (2008). Adult literacy education, gender equity and empowerment: Insights from a Freirean-inspired literacy programme. *Studies in the Education of Adults*, *40*(1), 24-39. https://doi.org/10.1080/02660830.2008.11661554

Reupert, A. (2018). Research that makes a difference. *Advances in Mental Health, 16*(2), 101-104. https://doi.org/10.1080/18387357.2018.1492513

Rich, M., & Ginsburg, K. R. (1999). The reason and rhyme of qualitative research: why, when, and how to use qualitative methods in the study of adolescent health. Journal of Adolescent health, 25(6), 371-378.

Rycroft-Malone, J., Burton, C. R., Bucknall, T., Graham, I. D., Hutchinson, A. M., & Stacey, D. (2016). Collaboration and co-production of knowledge in healthcare: opportunities and challenges. *International journal of health policy and management, 5*(4), 221. https://dx.doi.org/10.15171/ijhpm.2016.08

Sentell, T. L., & Halpin, H. A. (2006). Importance of adult literacy in understanding health disparities. *Journal of general internal medicine, 21*(8), 862-866. https://doi.org/10.1111/j.1525-1497.2006.00538.x

Slater, J. R. (2017). Social constructionism, in M. Allen (Eds.), *The SAGE encyclopedia of communication research methods* (pp. 1623-1628).

Social Care Institute for Excellence. (2015). *Co-production in social care: What it is and how to do it (*Guide 51). SCIE. https://www.scie.org.uk/publications/guides/guide51/files/guide51.pdf

Sofaer, S. (1999). Qualitative methods: what are they and why use them*?. Health services research, 34*(5 Pt 2), 1101-118.

Stewart, L., Moher, D., & Shekelle, P. (2012). Why prospective registration of systematic reviews makes sense. *Systematic reviews, 1*(1), 1-4.

Sullivan, P. A. (1995). Social constructionism and literacy studies. *College English*, *57*(8), 950-959.

The Kings Fund. (2020). *What are health inequalities.* https://www.kingsfund.org.uk/publications/what-are-health-inequalities

Thorn, B. E., Day, M. A., Burns, J., Kuhajda, M. C., Gaskins, S. W., Sweeney, K., ... & Cabbil, C. (2011). Randomized trial of group cognitive behavioral therapy compared with a pain education control for low-literacy rural people with chronic pain. *Pain*, *152*(12), 2710-2720. https://doi.org/10.1016/j.pain.2011.07.007

Thomas-Hughes, H. (2018). Ethical 'mess' in co-produced research: reflections from a UK-based case study. *International Journal of Social Research Methodology*, *21*(2), 231-242. https://doi.org/10.1080/13645579.2017.1364065

Tuckerman, J., Kaufman, J., & Danchin, M. (2020). *How to use qualitative methods for health and health services research.* Sage.

Turnhout, E., Metze, T., Wyborn, C., Klenk, N., & Louder, E. (2020). The politics of co-production: participation, power, and transformation. *Current Opinion in Environmental Sustainability*, *42*, 15-21. https://doi.org/10.1016/j.cosust.2019.11.009

UNESCO (2021). *Literacy*. UNESCO Institute for Statistics. http://uis.unesco.org/en/topic/literacy

Vágvölgyi, R., Coldea, A., Dresler, T., Schrader, J., & Nuerk, H. C. (2016). A review about functional illiteracy: Definition, cognitive, linguistic, and numerical aspects. *Frontiers in psychology*, 1617. https://doi.org/10.3389/fpsyg.2016.01617

Valtin, R., Bird, V., Brooks, G., Brozo, B., Clement, C., Ehmig, S., & Tamburlini, G. (2016). European declaration on the right to literacy. *European Literacy Policy Network.* https://doi.org/10.25656/01:23731

Van Niekerk, W. J. (2005). *A social constructionist epistemology.* https://uir.unisa.ac.za/bitstream/handle/10500/928/03chapter3.pdf

Vincent, K., Carter, S., Steynor, A., Visman, E., & Wågsæther, K. L. (2020). Addressing power imbalances in co-production. *Nature Climate Change, 10(*10), 877-878. https://doi.org/10.1038/s41558-020-00910-w

Waite, K. R., Paasche-Orlow, M., Rintamaki, L. S., Davis, T. C., & Wolf, M. S. (2008). Literacy, social stigma, and HIV medication adherence. *Journal of general internal medicine, 23*(9), 1367-1372. https://dx.doi.org/10.1007%2Fs11606-008-0662-5

World Health Assembly. (2012 May 25). *The global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level.* Sixty-fifth world health assembly. http://www.who.int/mental_health/WHA65.4_resolution.pdf

World Health Organization and Calouste Gulbenkian Foundation. (2014) *Social determinants of mental health.* World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/112828/9789241506809_eng.pdf

World Health Organization. (2015). *Health literacy toolkit for low-and middle-income countries: A series of information sheets to empower communities and strengthen health systems. https://apps.who.int/iris/bitstream/handle/10665/205244/B5148.pdf?sequence=1&isAllowed=y*

Yardley, L. (2017). Demonstrating the validity of qualitative research. *The Journal of Positive Psychology, 12*(3), 295-296. https://doi.org/10.1080/17439760.2016.1262624

Appendix A

Mental Health and Social Inclusion author guidelines

Author responsibilities

Our goal is to provide you with a professional and courteous experience at each stage of the review and publication process. There are also some responsibilities that sit with you as the author. Our expectation is that you will:

- Respond swiftly to any queries during the publication process.
- Be accountable for all aspects of your work. This includes investigating and resolving any questions about accuracy or research integrity
- Treat communications between you and the journal editor as confidential until an editorial decision has been made.
- Read about our research ethics for authorship. These state that you must:
    - Include anyone who has made a substantial and meaningful contribution to the submission (anyone else involved in the paper should be listed in the acknowledgements).
    - Exclude anyone who hasn't contributed to the paper, or who has chosen not to be associated with the research.
- If your article involves human participants, you must ensure you have considered whether or not you require ethical approval for your research, and include this information as part of your submission. Find out more about informed consent.

Research and publishing ethics

Our editors and employees work hard to ensure the content we publish is ethically sound. To help us achieve that goal, we closely follow the advice laid out in the guidelines and flowcharts on the COPE (Committee on Publication Ethics) website.
We have also developed our research and publishing ethics guidelines. If you haven't already read these, we urge you to do so – they will help you avoid the most common publishing ethics issues.

A few key points:

- Any manuscript you submit to this journal should be original. That means it should not have been published before in its current, or similar, form. Exceptions to this rule are outlined in our pre-print and conference paper policies. If any substantial element of your paper has been previously published, you need to declare this to the journal editor upon submission. Please note, the journal editor may use Crossref Similarity Check to check on the originality of submissions received. This service compares submissions against a database of 49 million works from 800 scholarly publishers.
- Your work should not have been submitted elsewhere and should not be under consideration by any other publication.
- If you have a conflict of interest, you must declare it upon submission; this allows the editor to decide how they would like to proceed. Read about conflict of interest in our research and publishing ethics guidelines.
- By submitting your work to Emerald, you are guaranteeing that the work is not in infringement of any existing copyright.

Third party copyright permissions

Prior to article submission, you need to ensure you've applied for, and received, written permission to use any material in your manuscript that has been created by a third party. Please note, we are unable to publish any article that still has permissions pending. The rights we require are:

- Non-exclusive rights to reproduce the material in the article or book chapter.
- Print and electronic rights.
- Worldwide English-language rights.
- To use the material for the life of the work. That means there should be no time restrictions on its re-use e.g. a one-year licence.

We are a member of the International Association of Scientific, Technical, and Medical Publishers (STM) and participate in the STM permissions guidelines, a reciprocal free exchange of material with other STM publishers. In some cases, this may mean that you don't need permission to re-use content. If so, please highlight this at the submission stage.
Please take a few moments to read our guide to publishing permissions to ensure you have met all the requirements, so that we can process your submission without delay.

Open access submissions and information

All our journals currently offer two open access (OA) publishing paths; gold open access and green open access.

If you would like to, or are required to, make the branded publisher PDF (also known as the version of record) freely available immediately upon publication, you should select the gold open access route during the submission process.

If you've chosen to publish gold open access, this is the point you will be asked to pay the APC (article processing charge). This varies per journal and can be found on our APC price list or on the editorial system at the point of submission. Your article will be published with a Creative Commons CC BY 4.0 user licence, which outlines how readers can reuse your work.

Alternatively, if you would like to, or are required to, publish open access but your funding doesn't cover the cost of the APC, you can choose the green open access, or self-archiving, route. As soon as your article is published, you can make the author accepted manuscript (the version accepted for publication) openly available, free from payment and embargo periods.

For UK journal article authors - if you wish to submit your work accepted by us to REF 2021, you must make a 'closed deposit' of your accepted manuscript to your respective institutional repository upon acceptance of your article. Articles accepted for publication after 1st April 2018 should be deposited as soon as possible, but no later than three months after the acceptance date. For further information and guidance, please refer to the REF 2021 website.

You can find out more about our open access routes, our APCs and waivers and read our FAQs on our open research page.

Find out about open

Transparency and Openness Promotion (TOP) Guidelines

We are a signatory of the Transparency and Openness Promotion (TOP) Guidelines, a framework that supports the reproducibility of research through the adoption of transparent research practices. That means we encourage you to:

- Cite and fully reference all data, program code, and other methods in your article.
- Include persistent identifiers, such as a Digital Object Identifier (DOI), in references for datasets and program codes. Persistent identifiers ensure future access to unique published digital objects, such as a piece of text or datasets. Persistent identifiers are assigned to datasets by digital archives, such as institutional repositories and partners in the Data Preservation Alliance for the Social Sciences (Data-PASS).
- Follow appropriate international and national procedures with respect to data protection, rights to privacy and other ethical considerations, whenever you cite data. For further

guidance please refer to our research and publishing ethics guidelines. For an example on how to cite datasets, please refer to the references section below.

Prepare your submission

Manuscript support services

We are pleased to partner with Editage, a platform that connects you with relevant experts in language support, translation, editing, visuals, consulting, and more. After you've agreed a fee, they will work with you to enhance your manuscript and get it submission-ready.

This is an optional service for authors who feel they need a little extra support. It does not guarantee your work will be accepted for review or publication.

Visit Editage

Manuscript requirements

Before you submit your manuscript, it's important you read and follow the guidelines below. You will also find some useful tips in our structure your journal submission how-to guide.

Format	Article files should be provided in Microsoft Word format While you are welcome to submit a PDF of the document alongside the Word file, PDFs alone are not acceptable. LaTeX files can also be used but only if an accompanying PDF document is provided. Acceptable figure file types are listed further below.
Article length / wordcount	Articles should be between 2000 and 5500 words in length. This includes all text, for example, the structured abstract, references, all text in tables, and figures and appendices. Please allow 350 words for each figure or table.
Article title	A concisely worded title should be provided.
Author details	The names of all contributing authors should be added to the ScholarOne submission; please list them in the order in which you'd like them to be published. Each contributing author will need their own ScholarOne author account, from which we will extract the following details: • Author email address. • Author name. We will reproduce it exactly, so any middle names and/or initials they want featured must be included. • Author affiliation. This should be where they were based when the research for the paper was conducted. In multi-authored papers, it's important that ALL authors that have made a significant contribution to the paper are listed. Those who have provided

	support but have not contributed to the research should be featured in an acknowledgements section. You should never include people who have not contributed to the paper or who don't want to be associated with the research. Read about our research ethics for authorship.
Biographies and acknowledgements	If you want to include these items, save them in a separate Microsoft Word document and upload the file with your submission. Where they are included, a brief professional biography of not more than 100 words should be supplied for each named author.
Research funding	Your article must reference all sources of external research funding in the acknowledgements section. You should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.
Structured abstract	All submissions must include a structured abstract, following the format outlined below. These four sub-headings and their accompanying explanations must always be included: ● Purpose ● Design/methodology/approach ● Findings ● Originality The following three sub-headings are optional and can be included, if applicable: ● Research limitations/implications ● Practical implications ● Social implications You can find some useful tips in our write an article abstract how-to guide. The maximum length of your abstract should be 250 words in total, including keywords and article classification (see the sections below).
Keywords	Your submission should include up to 12 appropriate and short keywords that capture the principal topics of the paper. Our Creating an SEO-friendly manuscript how to guide contains some practical guidance on choosing search-engine friendly keywords. Please note, while we will always try to use the keywords you've suggested, the in-house editorial team may replace some of them with

	matching terms to ensure consistency across publications and improve your article's visibility.
Article classification	During the submission process, you will be asked to select a type for your paper; the options are listed below. If you don't see an exact match, please choose the best fit: • Research Paper • Case Study • Practitioner Paper • Critique • Book Review • Review You will also be asked to select a category for your paper. The options for this are listed below. If you don't see an exact match, please choose the best fit: Research paper. Reports on any type of research undertaken by the author(s), including: • The construction or testing of a model or framework • Action research • Testing of data, market research or surveys • Empirical, scientific or clinical research • Papers with a practical focus Viewpoint. Covers any paper where content is dependent on the author's opinion and interpretation. This includes journalistic and magazine-style pieces. Technical paper. Describes and evaluates technical products, processes or services. Conceptual paper. Focuses on developing hypotheses and is usually discursive. Covers philosophical discussions and comparative studies of other authors' work and thinking. Case study. Describes actual interventions or experiences within organizations. It can be subjective and doesn't generally report on research. Also covers a description of a legal case or a hypothetical case study used as a teaching exercise. Literature review. This category should only be used if the main purpose of the paper is to annotate and/or critique the literature in a particular field. It could be a selective bibliography providing advice on information sources, or the paper may aim to cover the main contributors to the development of a topic and explore their different views. General review. Provides an overview or historical examination of some concept, technique or phenomenon. Papers are likely to be more descriptive or instructional ('how to' papers) than discursive.

Headings	Headings must be concise, with a clear indication of the required hierarchy. The preferred format is for first level headings to be in bold, and subsequent sub-headings to be in medium italics.
Notes/endnotes	Notes or endnotes should only be used if absolutely necessary. They should be identified in the text by consecutive numbers enclosed in square brackets. These numbers should then be listed, and explained, at the end of the article.
Figures	All figures (charts, diagrams, line drawings, webpages/screenshots, and photographic images) should be submitted electronically. Both colour and black and white files are accepted. There are a few other important points to note: • All figures should be supplied at the highest resolution/quality possible with numbers and text clearly legible. • Acceptable formats are .ai, .eps, .jpeg, .bmp, and .tif. • Electronic figures created in other applications should be supplied in their original formats and should also be either copied and pasted into a blank MS Word document, or submitted as a PDF file. • All figures should be numbered consecutively with Arabic numerals and have clear captions. • All photographs should be numbered as Plate 1, 2, 3, etc. and have clear captions.
Tables	Tables should be typed and submitted in a separate file to the main body of the article. The position of each table should be clearly labelled in the main body of the article with corresponding labels clearly shown in the table file. Tables should be numbered consecutively in Roman numerals (e.g. I, II, etc.). Give each table a brief title. Ensure that any superscripts or asterisks are shown next to the relevant items and have explanations displayed as footnotes to the table, figure or plate.
References	All references in your manuscript must be formatted using one of the recognised Harvard styles. You are welcome to use the Harvard style Emerald has adopted – we’ve provided a detailed guide below. Want to use a different Harvard style? That’s fine, our typesetters will make any necessary changes to your manuscript if it is accepted. Please ensure you check all your citations for completeness, accuracy and consistency; this

	enables your readers to exploit the reference linking facility on the database and link back to the works you have cited through CrossRef. Emerald’s Harvard referencing style References to other publications in your text should be written as follows: • Single author: (Adams, 2006) • Two authors: (Adams and Brown, 2006) • Three or more authors: (Adams *et al.*, 2006) Please note, ‘*et al*' should always be written in italics. A few other style points. These apply to both the main body of text and your final list of references. • When referring to pages in a publication, use ‘p.(page number)’ for a single page or ‘pp.(page numbers)’ to indicate a page range. • Page numbers should always be written out in full, e.g. 175-179, not 175-9. • Where a colon or dash appears in the title of an article or book chapter, the letter that follows that colon or dash should always be lower case. • When citing a work with multiple editors, use the abbreviation ‘Ed.s’. At the end of your paper, please supply a reference list in alphabetical order using the style guidelines below. Where a DOI is available, this should be included at the end of the reference.
For books	Surname, initials (year), *title of book*, publisher, place of publication. e.g. Harrow, R. (2005), *No Place to Hide*, Simon & Schuster, New York, NY.
For book chapters	Surname, initials (year), "chapter title", editor's surname, initials (Ed.), *title of book*, publisher, place of publication, page numbers. e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", Stankosky, M. (Ed.), *Creating the Discipline of Knowledge Management*, Elsevier, New York, NY, pp.15-20.
For journals	Surname, initials (year), "title of article", *journal name*, volume issue, page numbers. e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", *Journal of Consumer Marketing*, Vol. 22 No. 2, pp.72-80.
For published conference proceedings	Surname, initials (year of publication), "title of paper", in editor’s surname, initials (Ed.), *title of published proceeding which may include place and date(s) held*, publisher, place of publication, page numbers. e.g. Wilde, S. and Cox, C. (2008), “Principal factors contributing to the competitiveness of tourism destinations at varying stages of development”, in Richardson, S., Fredline, L., Patiar A., & Ternel, M. (Ed.s), *CAUTHE 2008: Where the 'bloody hell' are we?*, Griffith University, Gold Coast, Qld, pp.115-118.

For unpublished conference proceedings	Surname, initials (year), "title of paper", paper presented at [name of conference], [date of conference], [place of conference], available at: URL if freely available on the internet (accessed date). e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).
For working papers	Surname, initials (year), "title of article", working paper [number if available], institution or organization, place of organization, date. e.g. Moizer, P. (2003), "How published academic research can inform policy decisions: the case of mandatory rotation of audit appointments", working paper, Leeds University Business School, University of Leeds, Leeds, 28 March.
For encyclopaedia entries (with no author or editor)	*Title of encyclopaedia* (year), "title of entry", volume, edition, title of encyclopaedia, publisher, place of publication, page numbers. e.g. *Encyclopaedia Britannica* (1926), "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp.765-771. (for authored entries, please refer to book chapter guidelines above)
For newspaper articles (authored)	Surname, initials (year), "article title", *newspaper*, date, page numbers. e.g. Smith, A. (2008), "Money for old rope", *Daily News*, 21 January, pp.1, 3-4.
For newspaper articles (non-authored)	*Newspaper* (year), "article title", date, page numbers. e.g. *Daily News* (2008), "Small change", 2 February, p.7.
For archival or other unpublished sources	Surname, initials (year), "title of document", unpublished manuscript, collection name, inventory record, name of archive, location of archive. e.g. Litman, S. (1902), "Mechanism & Technique of Commerce", unpublished manuscript, Simon Litman Papers, Record series 9/5/29 Box 3, University of Illinois Archives, Urbana-Champaign, IL.
For electronic sources	If available online, the full URL should be supplied at the end of the reference, as well as the date that the resource was accessed. Surname, initials (year), “title of electronic source”, available at: persistent URL (accessed date month year).

	e.g. Weida, S. and Stolley, K. (2013), “Developing strong thesis statements”, available at: https://owl.english.purdue.edu/owl/resource/588/1/ (accessed 20 June 2018) Standalone URLs, i.e. those without an author or date, should be included either inside parentheses within the main text, or preferably set as a note (roman numeral within square brackets within text followed by the full URL address at the end of the paper).
For data	Surname, initials (year), *title of dataset*, name of data repository, available at: persistent URL, (accessed date month year). e.g. Campbell, A. and Kahn, R.L. (2015), *American National Election Study, 1948*, ICPSR07218-v4, Inter-university Consortium for Political and Social Research (distributor), Ann Arbor, MI, available at: https://doi.org/10.3886/ICPSR07218.v4 (accessed 20 June 2018)

Submit your manuscript

There are a number of key steps you should follow to ensure a smooth and trouble-free submission.

Double check your manuscript

Before submitting your work, it is your responsibility to check that the manuscript is complete, grammatically correct, and without spelling or typographical errors. A few other important points:

- Give the journal aims and scope a final read. Is your manuscript definitely a good fit? If it isn’t, the editor may decline it.
- Does your manuscript comply with our research and publishing ethics guidelines?
- Have you cleared any necessary publishing permissions?
- Have you followed all the formatting requirements laid out in these author guidelines?
- Does the manuscript contain any information that might help the reviewer identify you? This could compromise the blind peer review process (if requested by the author). A few tips:
    - If you need to refer to your own work, use wording such as ‘previous research has demonstrated’ not ‘our previous research has demonstrated’.
    - If you need to refer to your own, currently unpublished work, don’t include this work in the reference list.
    - Any acknowledgments or author biographies should be uploaded as separate files.
    - Carry out a final check to ensure that no author names appear anywhere in the manuscript. This includes in figures or captions.

You will find a helpful submission checklist on the website Think.Check.Submit.

The submission process

All manuscripts should be submitted through our editorial system by the corresponding author.

A separate author account is required for each journal you submit to. If this is your first time submitting to this journal, please choose the Create an account or Register now option in the editorial system. If you already have an Emerald login, you are welcome to reuse the existing username and password here.

Please note, the next time you log into the system, you will be asked for your username. This will be the email address you entered when you set up your account.

Don't forget to add your ORCiD ID during the submission process. It will be embedded in your published article, along with a link to the ORCiD registry allowing others to easily match you with your work.
Don’t have one yet? It only takes a few moments to register for a free ORCiD identifier.

During the submission process, you will have the opportunity to indicate whether you would like to publish your paper via the gold open access route.

Visit the ScholarOne support centre for further help and guidance.

What you can expect next

You will receive an automated email from the journal editor, confirming your successful submission. It will provide you with a manuscript number, which will be used in all future correspondence about your submission. If you have any reason to suspect the confirmation email you receive might be fraudulent, please contact our Rights team.

Post submission

Review and decision process

Each submission is checked by one of the editors. At this stage, they may choose to decline or unsubmit your manuscript if it doesn’t fit the journal aims and scope, or they feel the language/manuscript quality is too low.
If they think it might be suitable for the publication, your manuscript will be reviewed by one of the editors or a member of the editorial board. Double-blind peer review can be performed at the request of the authors at the initial submission stage. Once these reviewers have provided their feedback, the editor may decide to accept your manuscript, request minor or major revisions, or decline your work.

While all journals work to different timescales, the goal is that the editor will inform you of their first decision within 60 days.

During this period, we will send you automated updates on the progress of your manuscript via our submission system, or you can log in to check on the current status of your paper. Each time we contact you, we will quote the manuscript number you were given at the point of submission. If you receive an email that does not match these criteria, it could be fraudulent and we recommend you email permissions@emeraldinsight.com.

If your submission is accepted

Open access

If you’ve chosen to publish gold open access, this is the point you will be asked to pay the APC (article processing charge). This varies per journal and can be found on our APC price list or on the editorial system at the point of submission. Your article will be published with a Creative Commons CC BY 4.0 user licence, which outlines how readers can reuse your work.
For UK journal article authors - if you wish to submit your work accepted by Emerald to REF 2021, you must make a ‘closed deposit’ of your accepted manuscript to your respective institutional repository upon acceptance of your article. Articles accepted for publication after 1st April 2018 should be deposited as soon as possible, but no later than three months after the acceptance date. For further information and guidance, please refer to the REF 2021 website.

Copyright

All accepted authors are sent an email with a link to a licence form. This should be checked for accuracy, for example whether contact and affiliation details are up to date and your name is spelled correctly, and then returned to us electronically. If there is a reason why you can't assign copyright to us, you should discuss this with your journal content editor. You will find their contact details on the editorial team section above.

Proofing and typesetting

Once we have received your completed licence form, the article will pass directly into the production process. We will carry out editorial checks, copyediting, and typesetting and then return proofs to you (if you are the corresponding author) for your review. This is your opportunity to correct any typographical errors, grammatical errors or incorrect author details. We can't accept requests to rewrite texts at this stage.

When the page proofs are finalised, the fully typeset and proofed version of record is published online. This is referred to as the EarlyCite version. While an EarlyCite article has yet to be assigned to a volume or issue, it does have a digital object identifier (DOI) and is fully citable. It will be compiled into an issue according to the journal's issue schedule, with papers being added by chronological date of publication.

How to share your paper

Visit our author rights page to find out how you can reuse and share your work.
To find tips on increasing the visibility of your published paper, read about how to promote your work.

Correcting inaccuracies in your published paper

Sometimes errors are made during the research, writing and publishing processes. When these issues arise, we have the option of withdrawing the paper or introducing a correction notice. Find out more about our article withdrawal and correction policies.

Need to make a change to the author list? See our frequently asked questions (FAQs) below.

Frequently asked questions

Is there a submission fee for the journal?	The only time we will ever ask you for money to publish in an Emerald journal is if you have chosen to publish via the gold open access route. You will be asked to pay an APC (article processing charge) once your paper has been accepted (unless it is a sponsored open access journal). Read about our APCs At no other time will you be asked to contribute financially towards your article's publication. If you haven't chosen gold open access and you receive an email which appears to be from Emerald, asking you for payment to publish, please contact our Rights team.
How can I become a reviewer for a journal?	Please contact the editor for the journal, with a copy of your CV. You will find their contact details on the editorial team tab on this page.

Who do I contact if I want to find out which volume and issue my accepted paper will appear in?	Typically, papers are added to an issue according to their date of publication. If you would like to know in advance which issue your paper will appear in, please contact the content editor of the journal. You will find their contact details on the editorial team tab on this page. Once your paper has been published in an issue, you will be notified by email.
Who do I contact if I have a query about my submission?	Please email the journal editor – you will find their contact details on the editorial team tab on this page. If you ever suspect an email you've received from Emerald might not be genuine, you are welcome to verify it with the content editor for the journal, whose contact details can be found on the editorial team tab on this page. Alternatively, you can email our Rights team.
Is my paper suitable for the journal?	If you've read the aims and scope on the journal landing page and are still unsure whether your paper is suitable for the journal, please email the editor and include your paper's title and structured abstract. They will be able to advise on your manuscript's suitability. You will find their contact details on the Editorial team tab on this page.
How do I make a change to the list of authors once the manuscript has been submitted?	Authorship and the order in which the authors are listed on the paper should be agreed prior to submission. If you need to make any changes to the author information once the paper is under review or has been accepted, we will look into your request and closely follow the Committee on Publication Ethics (COPE) authorship guidelines. We will also require a statement from each author confirming their agreement.

Appendix B

Systematic review search terms

	Search Terms
Concept 1	illiteracy OR illiterate OR illiter* OR literacy
AND	
Concept 2	'mental health' OR anxiety OR depression OR panic OR 'obsessive compulsive disorder' OR 'post traumatic stress' OR bipolar OR psychosis OR schizophrenia OR psychiatric OR 'mental disorder' OR 'Mental illness'
AND	
Concept 3	prevalence OR incidence OR cohort OR 'cross sectional'

Appendix C

Systematic review quality assessment tool

Quality rating tool, influenced by existing tools such as AXIS, Critical Appraisal Skills Programme (CASP) cohort study checklist and The Newcastle-Ottawa (NOS).

		Yes	**No**
Study question	1. Did the study address a clearly focused issue?		
	2. Was an appropriate method used to answer the question?		
Sample	3. Was the study population and setting clearly specified and defined?		
	4. Were inclusion and exclusion criteria stated?		
Recruitment	5. Was the study population recruited in an acceptable way?		
	6. Was a sample size justification, power description, or variance and effect estimates provided?		
Validity	7. Was mental health measured in a standard, reliable, or appropriate way for all participants?		
Analysis	8. Was the statistical analysis adequately described and appropriate?		
	9. Were confounding factors controlled within the analysis?		
	10. Was there an assessment of statistical significance?		
	9-10 good quality, 7-8 were fair quality, 5-6 low quality, 4 and below considered as very poor/unacceptable.		

Critical Appraisal Skills Programme (2018). CASP Cohort Study Checklist. [online] Available at: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Cohort-Study-Checklist_2018.pdf

Downes, M.J., Brennan, M.L., Williams, H.C. and Dean, R.S. (2016). “Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS).” *BMJ open,* Vol. 6 No.12

Wells, G. A., Shea, B., O’Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2000). The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses

Appendix D

Breakdown of quality scores (systematic review)

Study	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10	Total score
Lincoln et al. 2021	1	1	1	0	1	0	1	1	1	0	**7**
Nguyen et al. 2017	1	1	1	1	1	0	1	1	1	1	**9**
Rong et al.2019	1	1	1	1	1	0	1	1	0	1	**8**
Liu et al. 2013	1	1	1	1	1	0	1	1	1	1	**9**
Baral and Bhagawati. 2019	**1**	**1**	**1**	**0**	**1**	**1**	**1**	**0**	**0**	**1**	**7**
Manandhar et al. 2019	1	1	1	1	1	1	1	1	1	1	**10**
Simkhada 2018	1	1	1	1	1	1	1	1	1	1	**10**
Basnet et al. 2018	0	1	1	0	1	0	1	1	1	0	**6**
Charoensakulchai et al. **2019**	1	1	1	1	1	0	1	1	1	1	**9**
Hassanzadeh et al. 2018	1	1	1	0	1	0	1	1	1	1	**8**
Gupta et al.2020	1	1	1	1	1	1	1	1	0	1	**9**
Firdaus 2017	1	1	1	0	1	0	1	1	1	1	**8**
Mathias et al. 2015	1	1	1	0	1	1	1	1	1	1	**9**
Kohli et al. 2013	1	1	1	1	1	1	1	0	1	1	**9**
Boakye-Yiadom et al. 2015	1	1	0	0	1	0	1	1	0	1	**6**
Farooq et al. 2019	1	1	1	0	1	1	1	1	1	1	**9**
Safi and Tariq 2013	1	1	1	1	1	0	1	0	0	1	**7**
Mubeen et al. 2012	1	1	1	0	1	1	1	0	0	1	**7**
Fortes et al. 2011	1	1	1	1	0	0	1	0	1	1	**7**

Appendix E

Society and Mental Health author guidelines

Manuscript Submission Guidelines:

All manuscripts must be submitted electronically via SAGEtrack's ScholarOne Manuscripts. To access this system, go to http://mc.manuscriptcentral.com/smh. You will be required to register with the system before electronically submitting your manuscript to *SMH*.

Ethics: Submission of a manuscript to another professional journal while it is under review by the *SMH* is regarded by the ASA as unethical. Significant findings or contributions that have already appeared (or will appear) elsewhere must be clearly identified. All persons who publish in ASA journals are required to abide by ASA guidelines and ethics codes regarding plagiarism and other ethical issues. This requirement includes adhering to ASA's stated policy on data-sharing: "As a regular practice, sociologists share data and pertinent documentation as an integral part of a research plan. Sociologists generally make their data available after completion of a project or its major publications, except where proprietary agreements with employers, contractors, or clients preclude such accessibility or when it is impossible to share data and protect the confidentiality of the research participants (e.g., field notes or detailed information from ethnographic interviews)" (ASA Code of Ethics, 2018).

Manuscript Preparation

Articles published in *Society and Mental Health* are seldom longer than 35 manuscript pages, including:

- title page
- abstract
- text
- notes
- references
- tables
- figures; and
- appendices

All pages must be typed double-spaced (including notes and references). Margins must be at least 1 inch (i.e., line length must not exceed 6-1/2 inches). Please use Times New Roman font, 12-point type size (roughly equivalent to 10-pitch type size).

The object is to provide reviewers and editors with easy-to-read text and space for notes. It is the responsibility of authors to submit manuscripts in the proper *SMH* format (see below). Manuscripts not submitted in *SMH* format may be returned for revision. Additional details on preparing and submitting manuscripts to *SMH* are published in the American Sociological Association Style Guide, 6th edition, available from the ASA Publications Department; phone: (202) 383-9005; email: publications@asanet.org.

***SMH* Format**

1. The title page should include the full title of the article, each author's complete name and institutional affiliation, total word count (include all text, notes, and references; do not include word counts for tables or figures), number of tables, number of figures, and running head (short title, fewer than 55 characters with spaces). Use an asterisk (*) to add a note to the title giving the corresponding author (name, address, phone, fax, and email). In the same note, cite acknowledgments, credits, or grants.
2. Print the abstract (fewer than 150 words) on a separate page headed by the title. Omit author identification.
3. The text of the manuscript should begin on a new page headed by the full title. Notes, references, tables, figures, and appendices appear in separate sections following the text, in that order. Since manuscripts are evaluated through an anonymous peer review process, authors should make every effort to remove identifying references or material. When citing your own work, please write "Smith (1992) concluded . . . ," but do not write "I concluded (Smith 1992) . . . "
4. Headings and subheadings in the text indicate the organization of content. Generally, three heading levels are sufficient.
5. Citations in the text should provide the last name of the author(s) and the year of publication. Include page numbers for direct quotes or specific passages. Cite only those works needed to provide evidence for your assertions and to

refer to important sources on the topic. In the following examples of text citations, ellipses (. . .) indicate manuscript text:

   1. If author’s name is in the text, follow it with the year in parentheses: “Duncan (1959) . . .”
   2. If author’s name is not in the text, enclose the last name and year in parentheses: “. . . (Gouldner 1963).”
   3. Pages cited follow the year of publication after a colon: “. . . (Ramirez and Weiss 1979:239–40).”
   4. Provide last names for joint authors: “. . . (Martin and Bailey 1988).”
   5. For three authors, list all three last names in the first citation in the text: “. . . (Carr, Smith, and Jones 1962).” For all subsequent citations use “et al.” throughout: “. . . (Carr et al. 1962).” For works with four or more authors, use “et al.” throughout.
   6. For institutional authorship, supply minimum identification from the complete citation: “. . . (U.S. Bureau of the Census 1963:117).”
   7. List a series of citations in alphabetical order or date order separated by semicolons: “. . . (Burgess 1968; Marwell et al. 1971).” Use consistent ordering throughout the manuscript.
   8. Use “forthcoming” to cite sources scheduled for publication. For dissertations and unpublished papers, cite the date. If no date, use “n.d.” in place of the date: “. . . Smith (forthcoming) and Oropesa (n.d.).”
   9. For machine-readable data files, cite authorship and date: “.|.|. (Institute for Survey Research 1976).”

6. Notes should be numbered in the text consecutively using superscript Arabic numerals. If referring to a note earlier or later in the text, use a parenthetical note: “. . . (see note 3).”
7. Equations in text must be typed. Use consecutive Arabic numerals in parentheses at the right margin to identify important equations.
8. Notes should be typed or printed, double-spaced, in a separate “NOTES” section and should appear after the text but before the references. Begin each note with the Arabic numeral to which it is keyed in the text (e.g., “1. After 1981, . . .”). Notes can (a) explain or amplify text, (b) cite materials of limited availability, or (c) append information presented in a table. Avoid long notes. Consider (a) stating in the text that information is available from the author, (b)

depositing the information in a national retrieval center and inserting an appropriate note, or (c) adding an appendix.

9. References follow the text in a separate section headed “REFERENCES.” All references cited in the text must be listed in the reference section, and vice versa. Publication information for each must be complete and correct. It is authors’ responsibility to make sure that all information provided in the reference section is complete and correct. List the references in alphabetical order by authors’ last names; include first names and middle initials for all authors. If there are two or more items by the same author(s), list them in order of year of publication. If the cited material is unpublished but has been accepted for publication, use “Forthcoming” in place of the date, and give the name of the journal or publishing house. For dissertations and unpublished papers, cite the date and place the paper was presented and/or where it is available. If no date is available, use “N.d.” in place of the date. If two or more works are by the same author(s) within the same year, list them in alphabetical order by title and distinguish them by adding the letters a, b, c, and so on, to the year (or to “Forthcoming” or “N.d.”). For works with multiple authors, only the name of the first author is inverted (e.g., “Jones, Arthur B., Colin D. Smith, and James Petersen.”). List all authors; using “et al.” in the reference section is not acceptable.
10. Number tables consecutively throughout the text. Insert a note in the text to indicate the placement (e.g., “Table 1 about here”). Type each table on a separate page. Each table must include a descriptive title and headings for columns and rows. Do not use abbreviations for variable names or column and row headings within tables. Align numbers in columns by decimal. Gather general notes to tables as “Note:”; use a, b, c, and so on, for table footnotes. Use asterisks *, **, and *** to indicate significance at the $p < .05$, $p < .01$, and the $p < .001$ levels, respectively, and specify one-tailed or two-tailed tests. Do not photo-reduce tables.
11. Number figures consecutively throughout the text. Insert a note in the text to indicate placement (e.g., “Figure 1 about here”). Each figure should include a title or caption. Do not use abbreviations within figures. All artwork must be submitted on diskette or as camera-ready art. Figures must be executed by computer or by graphic artist in black ink on white paper; lettering must be done in pen and ink or typeset; photographs must be black-and-white on

glossy paper. Contact the *SMH* office to discuss preferred file formats for computer generated files.

IMPORTANT: All figures (including all type) must be legible when reduced or enlarged to widths of 2-9/16 inches (one column width) or 5-5/16 inches (full page width).

PERMISSION: The author(s) are responsible for securing permission to reproduce all copyrighted figures or materials before they are published by *SMH*. A copy of the written permission must be included with the manuscript submission.

12. Appendices should be lettered to distinguish them from numbered tables and figures. Include a descriptive title for each appendix (e.g., "APPENDIX A. Variable Names and Definitions").

A few examples follow. Refer to the *American Sociological Association Style Guide* for more examples.

Books:

- Bernard, Claude. [1865] 1957. *An Introduction to the Study of Experimental Medicine*. Translated by Henry C. Greene. New York: Dover.
- House, James S. 1981. *Work Stress and Social Support*. Reading, MA: Addison-Wesley. U.S. Bureau of the Census. 1960. *Characteristics of the Population*. Vol. 1. Washington, DC: U.S. Government Printing Office.

Periodicals:

- Conger, Rand D. Forthcoming. "The Effects of Positive Feedback on Direction and Amount of Verbalization in a Social Setting." *Sociological Perspectives*.
- Goodman, Leo A. 1947a. "The Analysis of Systems of Qualitative Variables When Some of the Variables Are Unobservable. Part I—A Modified Latent Structure Approach." *American Journal of Sociology* 79:1179–1259.
- Goodman, Leo A. 1947b. "Exploratory Latent Structure Analysis Using both Identifiable and Unidentifiable Models." *Biometrika* 61:215–31.

Collections:

- Clausen, John A. 1972. “The Life Course of Individuals.” Pp. 457–514 in *Aging and Society*, vol. 3, *A Sociology of Age Stratification*, edited by M. W. Riley, M. Johnson, and A. Foner. New York: Russell Sage.

Dissertations:

- Charles, Maria. 1990. “Occupational Sex Segregation: A Log-Linear Analysis of Patterns in 25 Industrial Countries.” Ph.D. dissertation, Department of Sociology, Stanford University, Stanford, CA.

Machine-Readable Data Files:

- American Institute of Public Opinion. 1976. *Gallup Public Opinion Poll #965* [MRDF]. Princeton, NJ: American Institute of Public Opinion [producer]. New Haven, CT: Roper Public Opinion Research Center, Yale University [distributor].
- Miller, Warren, Arthur Miller, and Gerald Klein. 1975. *The CPS 1974 American National Election Study* [MRDF]. Ann Arbor, MI: Center for Political Studies, University of Michigan [producer]. Ann Arbor, MI: Interuniversity Consortium for Political and Social Research [distributor].

Electronic Sources

- American Sociological Association. 1997. “Call for Help: Social Science Knowledge on Race, Racism, and Race Relations” (ASA Action Alert, October 15). Washington, DC: American Sociological Association. Retrieved October 15, 1997 (http://www.asanet.org/racecall.htm).
- Kao, Grace and Jennifer Thompson. 2003. “Racial and Ethnic Stratification in Educational Achievement and Attainment.” Annual Review of Sociology 29:417–42. Retrieved October 20, 2003 (http://arjournals.annualreviews.org/doi/abs/10.1146/annurev.soc.29.01020...).

Orcid

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

Appendix F

Study Poster

University of East Anglia

Version 1 (07/10/2019): IRAS ID 274779

Lets Talk Literacy

Can you recall a time when your service users have had literacy difficulties but have not been forthcoming about these?

We are interested in staffs experience of identifying and supporting service users who have literacy difficulties where no formal Learning Disability is present.

Together with the Green Light Champions we want to raise awareness of unrecognised literacy difficulties and understand how clinicians experience this in service user contacts.

WE NEED YOU!

For more information please ask your team Green Light Champion or contact the researcher for more information.

Lucy Hunn

L.hunn@uea.ac.uk

Appendix G

Participant information sheet

Lets Talk Literacy Research Project

PARTICIPANT INFORMATION SHEET

You are being invited to be involved in this qualitative research study looking at clinician's experience of working with people who have reading and writing difficulties and are accessing mental health services within [trust name removed to maintain confidentiality].

Before agreeing to take part in the study you should understand why the research is being carried out and what it would involve for you. Please take time to read the information below carefully. If you have any questions about the research please feel free to ask the researcher.

What's the purpose of the research?
This research has been inspired by the Green Light Champion Network (GLCN) who champion for improving accessibility of our services. Anecdotally staff report that they often find that individuals they are supporting within our mental health services have difficulties with literacy. National and local policies state that we should be identifying individuals needs and providing a service that meets this. However, there are no guidelines on how we should identify someone's literacy abilities or how to make adjustments to support these individuals.

This study wants to explore clinicians experience of identifying literacy difficulties in our service users. What are clinicians doing in order to identify literacy difficulties, what is helpful or unhelpful in this process. It is hoped that the research will also gather information on what else may play a role in these situations and how therapeutic relationship building and recovery outcomes may be impacted on.

Why have you been invited to take part?
You have been given this information sheet and invited to participate because this study is looking for clinicians within [trust name removed to maintain confidentiality] who have experience of working with individuals who have literacy difficulties but do not have a primary Learning Disability diagnosis. We would like participants to have at least one years' experience of working within NHS mental health services and have face to face, ongoing contact with service users.

What's involved?
Participants who want to be involved in this study will need to sign a consent form. Following this an interview will be arranged between the researcher and yourself. It is likely that the interview will last approximately 45 minutes. There will be a short questionnaire about your experiences to complete prior to the interview and there will be a chance to have a debrief after the interview. It is likely that the entire process would take up no more than 80 minutes of your time. The interviews will take place at your place of work or via telephone/

video calling and will focus on your experiences of identifying and supporting individuals with literacy difficulties.

The interviews will be audio recorded and transcribed for data analysis at which point they will be anonymised. Participants will have the opportunity to comment on the themes drawn out from across all the participant interviews before the results are finalised.

Why take part?

Taking part in this research study will give you the opportunity to have your voice heard and share your knowledge and understanding. It is hoped that this research will help to inform policy and education with in the trust and you can help shape this.

Do I have to take part?

It is not mandatory for any staff members to take part in this research study. Involvement in the study is voluntary. If you do take part you can withdraw at any point up until 2 weeks after the interview takes place. At this point you would not be able to withdraw from the study as once the interview has been transcribed and anonymised it would be impossible to retrieve the data.

What will happen to my data?

Interviews will be recorded on an audio recorder. Audio files will be immediately transferred on to a password protected computer and saved on a password-encrypted memory stick. At the point of transcription (two weeks after the interview) transcriptions will be anonymised. Direct quotes may be used in the publication of this study but no names will be used so participants will not be identifiable. Transcripts and recordings will be kept in a locked filing cabinet and according to the UEA data management policy will be destroyed after 10 years.

We will need to use information from the interviews for this research project. This information will include your name and demographic information. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to researchsponsor@uea.ac.uk

- by contacting UEA Data Protection Officer: Ellen Paterson, The Library, University of East Anglia, Norwich Research Park, Norwich NR4 7TJ, dataprotection@uea.ac.uk, 01603 592431.

Who has reviewed the study?
This study has been reviewed and given permission to continue by the University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee. The study has also gained approval from the Health Research Authority.

What will happen with the findings?
The research will be written up in journal publication format and submitted for publication. The information will also be fed back to the Research and development team with a summary. The research team hope to create a video to share the findings with the general population.

Researcher contact details
Lucy Hunn
University of East Anglia
l.hunn@uea.ac.uk

Research supervisor
Dr Bonnie Teague
University of East Anglia
B.Teague@uea.ac.uk

Thank you for taking the time to read this information sheet

Appendix H
Topic guide

Clinician’s experience

Tell me about your experiences of working with people who have literacy needs

Prompts: How did you first identify that there were literacy needs?

How did you make adjustments to involve these individuals in their care?

Societal factors

Why do you think people don’t typically identify themselves as having literacy difficulties to clinicians?

Prompts: From your own experiences do you agree with this viewpoint?

Do you think mental health impacts on literacy abilities or vice versa? Why do you think this from your experience?

Change and improvement

What are the specific or unique needs of someone who has both literacy and mental health difficulties?

Prompts: As an organisation what do we need to do to maximise individuals’ engagement and empowerment within services if they have literacy difficulties?

Appendix I

Participant demographics questionnaire

What is your current clinical role: ____

What team or specialist area do you work in?____

What age range does your team provide services for: ________________________________

How many years of experience do you have working in mental health services? ___________

Do you have experience of working with individuals with literacy difficulties? (Please circle)

Yes No

Appendix J

Consent form

Participant ID: ________________________________

Title of Project: Let's talk literacy

Name of Researcher: Lucy Hunn (L.hunn@uea.ac.uk) Please initial box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I confirm that I am signing this consent form at least 48 hours after having first had the study explained to me. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
4. I understand that the interview will be audio recorded and the file will be stored securely ☐
5. I understand that I can change my mind and withdraw my interview data from the study up to 14 days after the interview. It will be my responsibility to contact the researcher to let them know. ☐
6. I understand that a pseudonym will be used. I understand that direct quotes may be used in the publication of this research but that any potentially identifiable information will be removed or changed to protect confidentiality ☐
7. I understand that the summary research findings will be disseminated to [trust name removed to maintain confidentiality] and wider audiences, including submission for publication in a journal ☐
8. I agree to take part in the above study. ☐

________ ________ ________

Name of Participant Date Signature

________ ________ ________

Name of Researcher Date Signature

Appendix K

University of East Anglia FMH ethical approval

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

NORWICH MEDICAL SCHOOL
Bob Champion Research & Educational Building
James Watson Road
University of East Anglia
Norwich Research Park
Norwich NR4 7UQ

NORWICH MEDICAL SCHOOL
Bob Champion Research & Educational Building
James Watson Road
University of East Anglia
Norwich Research Park
Norwich NR4 7UQ

Email: fmh.ethics@uea.ac.uk
www.med.uea.ac.uk

Lucy Hunn
Medical School
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ

17th October 2019

Dear Lucy

Clinician Insights into the Impact of Literacy Difficulties on Service Users Engaging with Mental Health Services (Let's talk literacy)

Reference: 160

Thank you for your letter and email dated 11th October 2019 addressing the Committee's concerns. These have been considered and I can now confirm that your proposal has been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

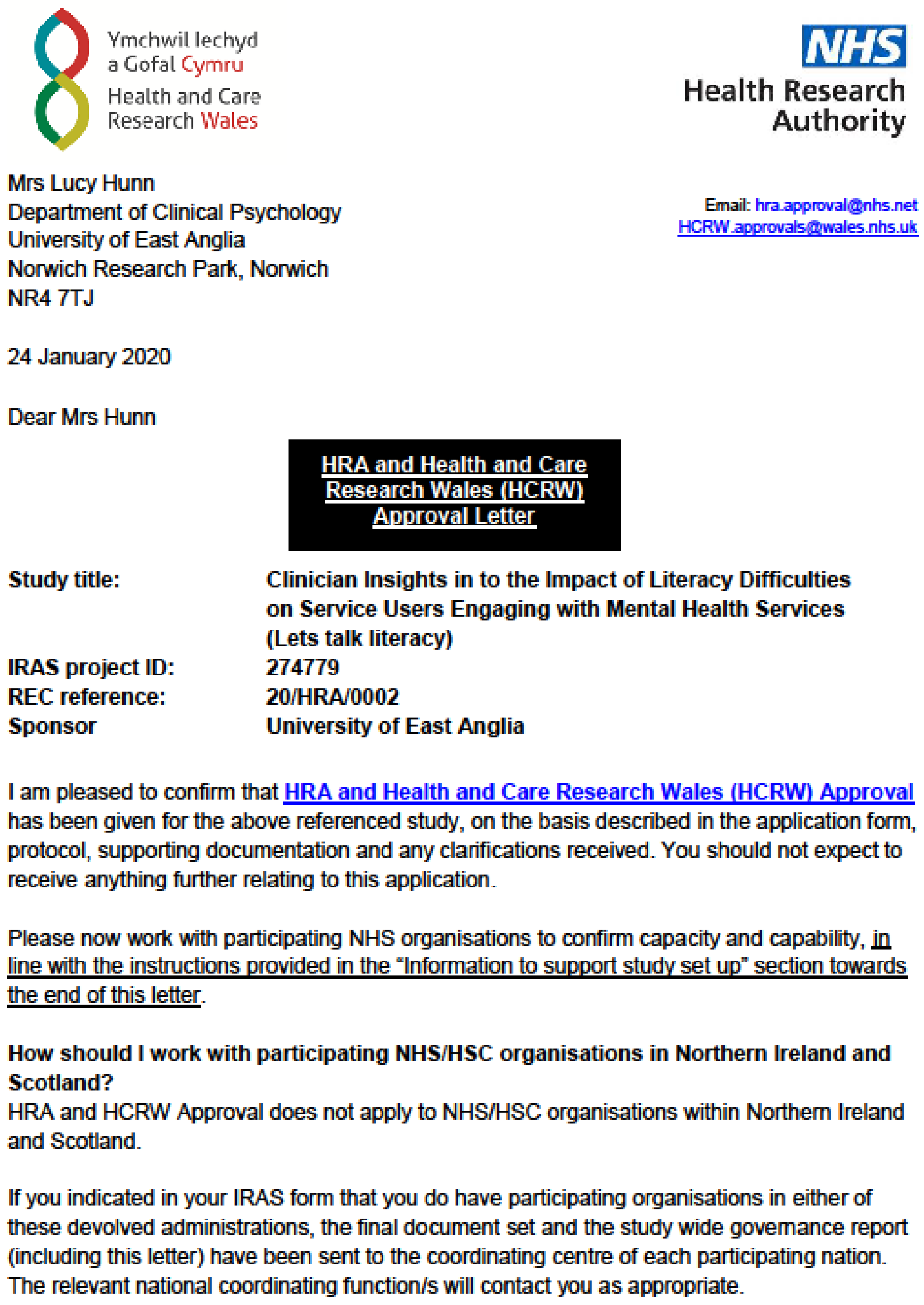
Please can you arrange to send us a report once your project is completed.

Yours sincerely

Prof Alastair Forbes
Chair
FMH Research Ethics Committee

Appendix L

Health Registration Authority ethical approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mrs Lucy Hunn
Department of Clinical Psychology
University of East Anglia
Norwich Research Park, Norwich
NR4 7TJ

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

24 January 2020

Dear Mrs Hunn

HRA and Health and Care Research Wales (HCRW) Approval Letter

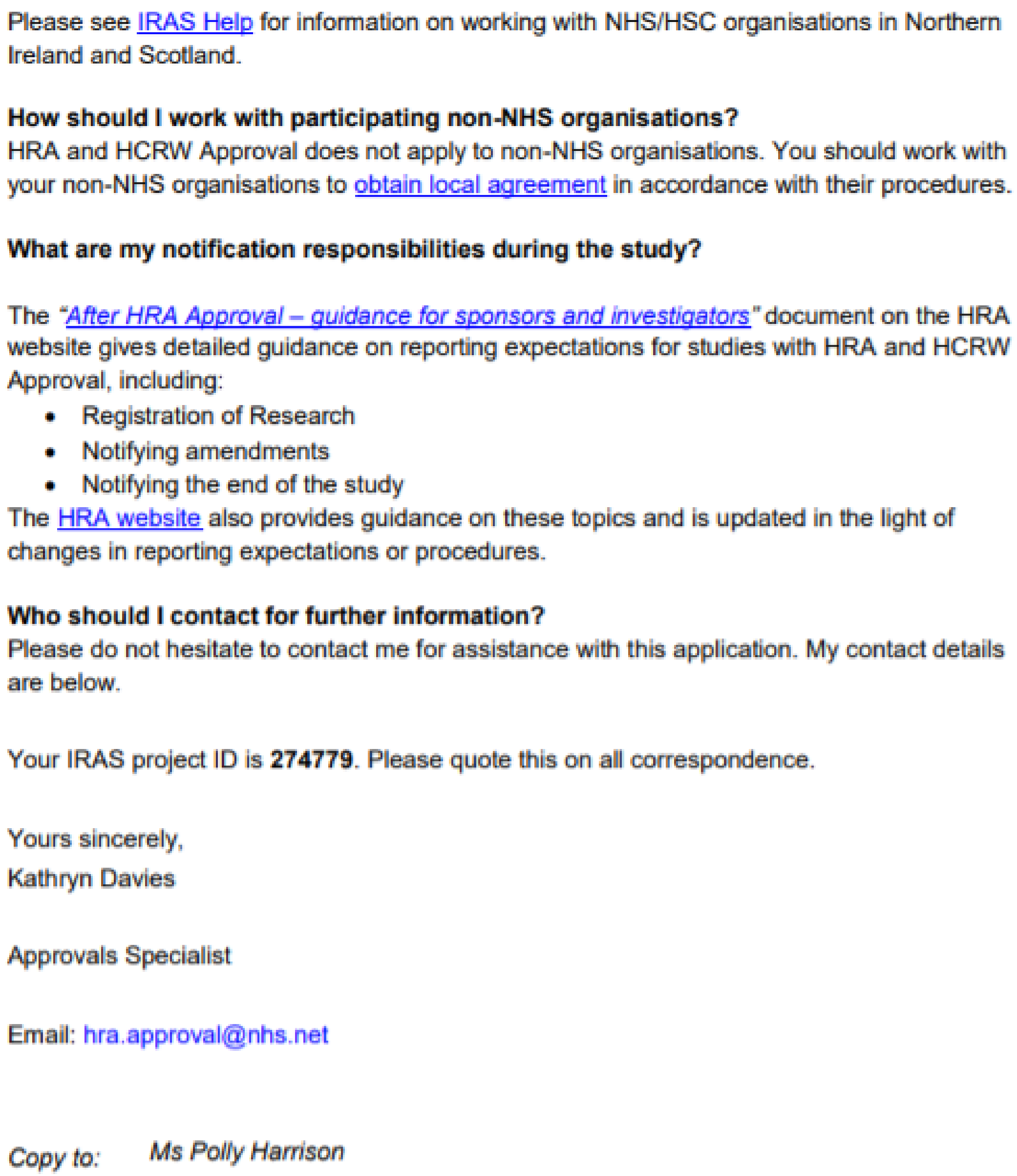
Study title:	**Clinician Insights in to the Impact of Literacy Difficulties on Service Users Engaging with Mental Health Services (Lets talk literacy)**
IRAS project ID:	**274779**
REC reference:	**20/HRA/0002**
Sponsor	**University of East Anglia**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

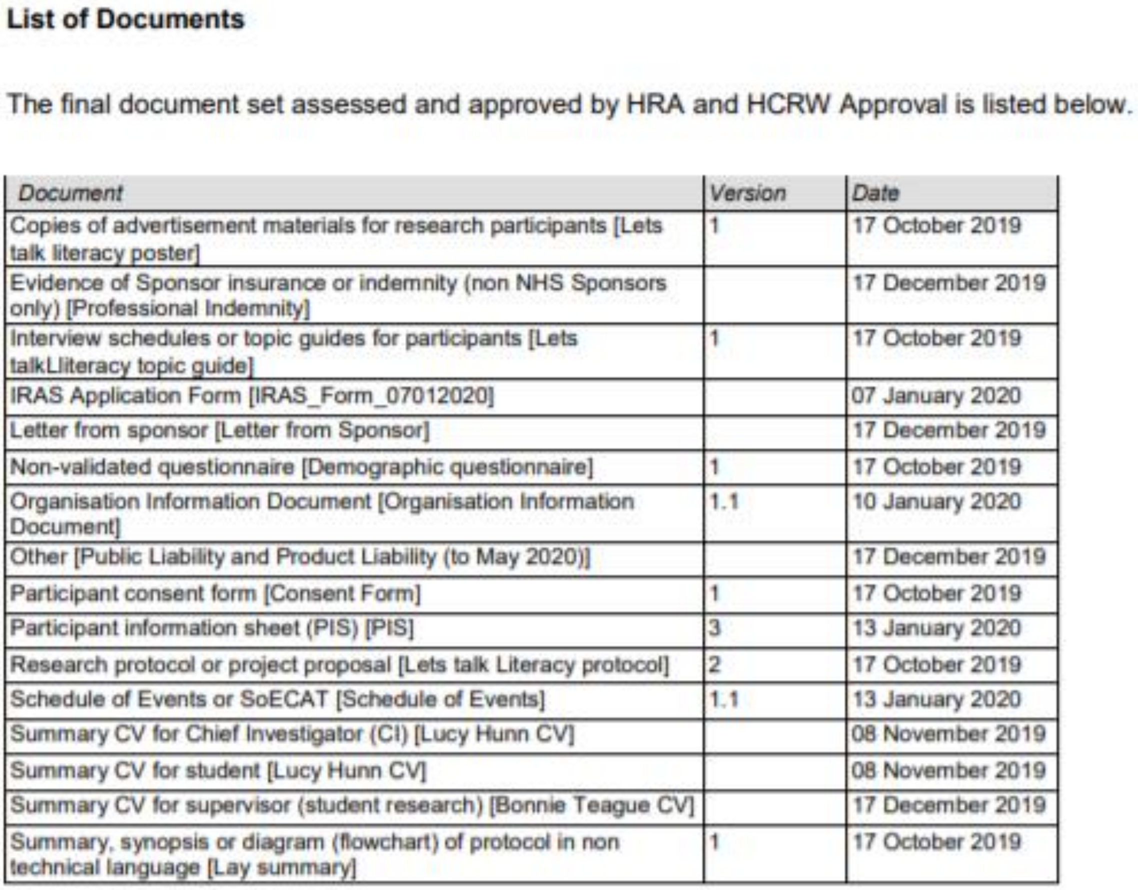
Your IRAS project ID is **274779**. Please quote this on all correspondence.

Yours sincerely,
Kathryn Davies

Approvals Specialist

Email: hra.approval@nhs.net

Copy to: *Ms Polly Harrison*



List of Documents

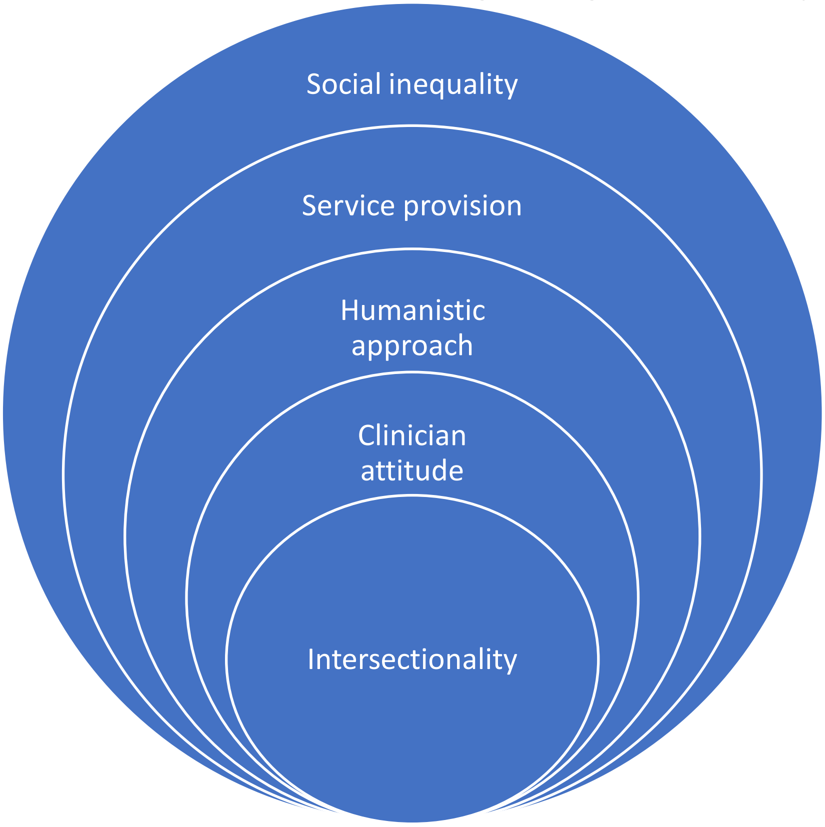
The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Lets talk literacy poster]	1	17 October 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity]		17 December 2019
Interview schedules or topic guides for participants [Lets talkLliteracy topic guide]	1	17 October 2019
IRAS Application Form [IRAS_Form_07012020]		07 January 2020
Letter from sponsor [Letter from Sponsor]		17 December 2019
Non-validated questionnaire [Demographic questionnaire]	1	17 October 2019
Organisation Information Document [Organisation Information Document]	1.1	10 January 2020
Other [Public Liability and Product Liability (to May 2020)]		17 December 2019
Participant consent form [Consent Form]	1	17 October 2019
Participant information sheet (PIS) [PIS]	3	13 January 2020
Research protocol or project proposal [Lets talk Literacy protocol]	2	17 October 2019
Schedule of Events or SoECAT [Schedule of Events]	1.1	13 January 2020
Summary CV for Chief Investigator (CI) [Lucy Hunn CV]		08 November 2019
Summary CV for student [Lucy Hunn CV]		08 November 2019
Summary CV for supervisor (student research) [Bonnie Teague CV]		17 December 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Lay summary]	1	17 October 2019

Appendix M

Diagrammatic representation of themes

This diagram depicts the five main themes that arose from the transcripts. They are represented in a systems diagram with the individual at the centre of the diagram in line with the overall person-centred approach that this research project took. The diagram shows how participant responses reflected that they felt individual clinician attitudes and a humanistic approach are often wrapped around an individual in an attempt to protect them from inaccessible service provision and stigmatising views of society.



Intersectionality: Participants described how they viewed the combination and interdependence of literacy difficulties and mental health difficulties on each other creates a global impact on an individual's life and identity.

Clinician attitude: Participants described an emotional response to difficulties faced by individuals with literacy difficulties and the need to go the extra mile to advocate for them.

Participants also reflected on how they felt staff pressures and service structure meant they could not always provide appropriate person-centred care.

Humanistic approach: Participants described how an ongoing individualised approach that encompasses a willingness for flexibility and a focus on connection over procedure and curiosity over assumptions could help achieve person-centred care. They felt this humanistic approach could empower individuals to take an active role in shaping their care and address some of the barriers experienced by those with literacy difficulties within services and society.

Service provision: Participants voiced feeling that service structures are often based on assumptions of literacy and in doing this they risk disempowering and potential causing iatrogenic harm to those with literacy difficulties.

Social Inequality: Participants strongly indicated that they felt society creates a stigma and discriminates against those with literacy difficulties, leading them to experience cultural and structural barriers to comprehensive inclusion in life.

Appendix N

Theme frameworks

Main theme: Intersectionality of mental health and literacy difficulties

Agreed Definition: The combination and interdependence of literacy difficulties and mental health difficulties creates a global impact on an individual's life generally and within mental health services

Sub-Codes within Theme:	**Transcripts which covered subtheme**
Mental health impacts on cognition for literacy skills	All
Literacy difficulties impact on mental health (internalised)	All
Holistic impact of literacy difficulties and consequent impact on identity (self-stigma)	1, 2, 3, 5, 7, 8, 9
Mental health can overshadow literacy difficulties (unmet need)	2, 3, 6, 8, 9
Impact of literacy difficulties becomes more complex as people age	1, 2, 5, 6, 7

Summary/Interpretation of Data:

Participants perceived that the state of an individual's mental health could impact on their literacy abilities. Participants spoke about how when an individual is suffering with their mental health it often impacts on the different cognitive skills required for literacy such as attention and recall. In addition to this it was discussed how an individual's literacy abilities could also impact on their mental health. Participants discussed how they perceived literacy difficulties to be isolating as well as how they might contribute to low self-esteem and a poor sense of self-worth. This intersectionality of literacy difficulties and mental health was recognised by participants as being, at least in part, due to the global impact of literacy difficulties on someone's life. Participants discussed, from their experience, the many challenges that an individual may face when they have literacy difficulties and the impact this can have on someone's identity.

Within mental health services participants discussed how due to staff training and the focus within our services being on mental health that at times literacy difficulties are likely to be missed. This may be because the individual's mental health is considered priority and unless an individual raises their literacy difficulties as being a contributing factor to this it may well be overlooked. In overlooking someone's literacy difficulties it was participants believed that this could lead to someone not receiving the appropriate person-centred care at a level that is accessible to them and thus further negatively impacting on their mental health.

Several of the participants worked in older adult services and they reflected their ideas of how this intersectionality might be experienced differently in our older clients. Literacy difficulties at this stage in life might be newly acquired due to conditions like dementia, or due to a loss of sight or hearing as a process of ageing. Participants reflected on how this might be experienced quite differently compared to an individual who has always experienced difficulties with literacy.

Quotes for each subtheme

Mental health cognition impacts on skills needed for literacy
“mean if you’re depressed and your senses are slowed down and you’re anxious and you can’t concentrate so all of those things will have an impact. If you’re in pain, if you’re experiencing chronic pain you wont be able to concentrate” Transcript 6 line 179-182

“And it’s like, I always equate it to juggling, you know, you’re juggling more and more stuff and if you put something in something’s got to give and it’s either normally memory or you know your ability to do this normal day to day things wash clean, read, write, you know something gives doesn’t it” Transcript 7 line 101-104

“who because of his level of depression you could put something in front of him and you know he would look at it and you could tell the intent was there to try and take it on but none of that was going in” Transcript 3 line 16-18

Literacy difficulties impacts on mental health
“you know if you struggle to read and write and yet you’re sat with a group of people that seem to be coping absolutely fine that’s then going to impact on your own mental health because you then start thinking them things are true that people have told you that you know you’re not intelligent or whatever so I think yeah it can have an affect both ways.” Transcript 4 line 111-116

“The confidence bit yes definitely, you know because the self-esteem, yeah you feel worthless that would definitely impact wouldn’t it” Transcript 5 line 94-95

“I think it has a tremendous impact on people because you would just feel excluded or isolated or lonely or not able to read or write to communicate with others that makes life incredibly isolating” Transcript 6 line 171-173

Holistic impact of literacy difficulties and consequent impact on life
“but ultimately she lost control through her sight, purpose, identity those kind of things, which impacted on her mental health and meant and meant that she couldn’t go home.
Researcher: So impacted on her life, every aspect of her life
Interviewee: Every aspect of her life and who she was” Transcript 2 line 146-151

“then you reside yourself to the fact that you’re never gonna understand and you can’t progress forward” Transcript 8 192-193

“he had a of moment where it wasn’t sort of exclusive to that contract it was a round this has you know in his words buggered my whole life up” Transcript 3 line 150-152

Mental health can overshadow literacy difficulties
“I think if you, I mean my experience if you come into mental health services and all the focus is on your mental health, something like literacy or numeracy problems either fall to the bottom of the list

or aren't picked, aren’t attended to, and I think that that's the reality really of mental health services pretty much” Transcript 9 line 161-165

“And then we, we often hear that sort of, then what happens then is like the person will decide to try and maybe divert attention from themselves because they're struggling so much. And so sometimes this is where we get a mistaken view that someone is hyperactive and got ADHD when in actual fact when you track it back and you really examine what was going on in the classroom…” Transcript 9 111-120

Impact of literacy difficulties becomes more complex as people age

“but I think they can accept it a little easier as its part of growing old” Transcript 2 line 124

“I can think of one guy in the one of the compassion focused therapy groups, where he used to be a GP and his wife used to be a nurse, so he’d gone from being, in terms of the WAIS, very high functioning to now not that high functioning, I think for him the fact that he was on the other side of the table but also that he couldn’t do what he used to do had a much bigger impact, he had difficulty with acceptance.“ Transcript 1 line 33-39

“so it’s not just the issue of how am I going to read this and understand, it is just how am I even going to remember that I have this sheet and things like that” Transcript 1 line 60-62

LTL Coding Summaries

Main theme: Clinician attitude

Agreed Definition: Individuals recognised an emotional response to difficulties faced by those with literacy difficulties and the need to go the extra mile to advocate for individuals with literacy difficulties. As well as recognising that as an organisation we aren't quite getting it right.

Sub-Codes within Theme:	**Transcripts which covered subtheme**
Strong emotional response	2, 3, 4, 5, 6, 7, 8, 9
Multiple pressures on staff lead to literacy not being a priority	5,6,7,9
Going the extra mile	2,5,7,8,9
Clinician's not feeling like they're able to care in the 'right' way	1,2,3,4,5, 6,7,8
Perceptions of literacy being difficult to ask about	1, 6, 7

Summary/Interpretation of Data

Many participants described a passion for working with individuals who have literacy difficulties and a sense of fighting for this population to get their needs met was evident. This sense of fighting appeared to exist within a context where not everyone is considering or making adjustments for individuals with literacy needs. As a consequence, participants gave examples where they felt a strong emotional reaction in response to situations where people with literacy needs had not had their needs met.

There was a sense that working with individuals with literacy needs often required more of staff, in terms of creatively making adaptations. Whilst the participants expressed a desire to go the extra mile to reach the needs of this population group there was also the recognition that there are so many competing demands on staff that it makes doing this very difficult.

Many participants reflected on how they feel like as individual clinicians they may be making good reasonable adjustments for individuals they are working with who have literacy difficulties but that we are not always getting it right. There was a sense that as an organisation we need to be doing more to reach these individual's needs.

Quotes for each subtheme

Strong emotional response

"it was just sheer frustration that he wasn't able to progress and he felt anywhere near his dreams with his current level of ability it was heart breaking but he's getting the right support now so we are pleased" Transcript 8 line 256-259

"I am very, I'm quite passionate about, when in the goals section it's their voice." Transcript 2 line 62-64

"You know I think it's one of them awful things isn't it, and we, it is just awful, and I think the more that is challenged the better, the more understanding people have over you know extra learning needs or however you want to put it then the less that stigmas going to be around" Transcript 4 line 80-84

Multiple pressures on staff lead to literacy not being a priority
"everyone is REALLY busy and under pressure so whose job is that, who's responsibility is that?" Transcript 6 line 238-239

"it's tricky, it's hard, you know, and if you're if you're, you know short staffed, and all the rest of it, and you're you know you're up against it basically in trying to treat someone with their mental illness, and I think the literacy you know literacy needs wouldn't even come on the agenda" Transcript 9 line 168-171

"1:1 time is so so important and with staff shortages its lacking at the moment it really is, you know the pressures on the ward those times are so important" Transcript 5 line 142-144

Going the extra mile
and if your easy read material isn't suitable go the extra mile and create the material that is really suitable for that patient Transcript 8 line 3332-334

I have been doing recently tailored care planning, so we'll go through the care planning and we'll look at easy read, so using a picture, even I've been going out and taking photographs Transcript 7 line 62-64

do not be judgemental be very considerate and really pull on all the extra resources that you can Transcript 8 line 36-37

Clinician's not feeling like they're able to care in the 'right' way
"I think we can we can always do more and find ways" Transcript 3 line 173-174

"I think we're getting better but we can always do more" Transcript 6 line 319

"Bit of an afterthought you know it's starting to role and it's starting to work but I don't think it's the top of peoples questioning really" Transcript 7 line 178-180

Perceptions of literacy being difficult to ask about
"I think that's another thing isn't it, you need to ask all the right questions so but it's a, I can see it's a potentially tricky question to approach really." Transcript 6 line 41-43

"it's like when you ask people if they're suicidal for the first time and you get really you know its quite an uncomfortable question to ask, I think it's the same around literacy, it's quite an uncomfortable question to ask because you take it as, that everybody’s been to school and stuff like that” Transcript 7 line 31-35

“I think sometimes if you’re not asked if you have a difficulty with this. I think it often a similar thing with trauma. I’m not saying people that are still disclosing might choose not to, but just to have that option, we’re meant to ask about if someone is physically or sexually abused in an assessment and I think that is often left off.” Transcript 1 line 76-81

Main theme: Humanistic approach

Agreed Definition: An ongoing individualised approach that encompasses a willingness for flexibility in which you adapt your care with a focus on connection over procedure and curiosity over assumptions whilst recognising individuals' inherent value. This humanistic approach aims to empower individuals to take an active role in shaping their care. This approach helps to address some of the barriers experienced by those with literacy difficulties.

Sub-Codes within Theme:	Transcripts which covered subtheme
Importance of a whole person approach/ holistic assessment	All
Importance of a trusting relationship between clinician and service user	1, 2, 3, 5, 6, 8, 9
Clinician's awareness of literacy difficulties-internal	All
Need to ask about literacy difficulties-actional	1, 2, 3, 4, 6, 7, 8, 9
Working with service users/experts by experience to inform service improvement	1,2,6
Being creative	All

Summary/Interpretation of Data

Participants expressed their views around the importance of a humanistic approach to deliver person-centred care within our services. There was emphasis on how we need to be taking a whole person approach to fully meet an individual's needs and this would encompass someone's literacy needs. However, participants spoke about how in order to recognise someone's literacy needs their needs to be a general awareness of literacy difficulties and how this might impact on an individual and their journey through care systems. Participants reflected on how some people may have greater awareness of literacy difficulties if this is something that they have personal or professional experience of.

Participants spoke about how important they perceived therapeutic relationships to be in order to build trust and a safe environment in which someone would feel comfortable to discuss their needs, including their literacy needs. There were common themes around how we need to be asking individuals about their literacy needs. There was also a reflation on how identifying literacy needs may also require being 'detectives', picking up on subtle ques that might indicate that someone has literacy difficulties.

Participants provided many examples of how individual clinicians work creatively to make adjustments to meet the needs of individuals with literacy needs. There were examples of current practise that clinicians are doing as well as suggestions for further work we could be doing in this area. There was a suggestion that we could be utilising servicer user experience more to develop our services and protocols to ensure that we are meeting this area of needs.

Quotes for each subtheme

Importance of a whole person approach/ holistic assessment
“I guess it’s an observation, almost you don’t have to ask them, you kind of its your clinical intuition, you get a feel for what someone is saying. Communication isn’t necessarily just through verbal kind of bits, certainly with OT there is lots of observations, yours assessing from the minute you meet them, and they don’t have to always say stuff.” Transcript 2 line 38-43

“again depends on what it is that that person struggles with, so it’s going to be different for everyone, it’s not going to be the same thing for each person” Transcript 4 line 147-149

Importance of a trusting relationship between clinician and service user
“people might tell you that you need to create the environment in which people would tell you” Transcript 6 line 94-95

“I mean, you've got to get a bit of rapport and you know, but it doesn't have to be, I mean, you could probably do it in the first assessment, I think I often do” Transcript 9 line 293-295

“once you start to build up a bit of a relationship with people they will open up” Transcript 5 line 51-52

Clinician’s awareness of literacy difficulties
“identify what you think might be an additional need which I think literacy problems are you can then offer additional support” Transcript 8 line 69-70

“So like I guess the way I work with them is influenced by, I used to work on an LD [learning disability] ward so I use some of the same strategies and techniques with them” Transcript 1 line 5-10

“I think actually it needs to be addressed with awareness so awareness and then additional training” Transcript 8 line 389-399

Need to ask about literacy difficulties
“First and foremost you ask them” Transcript 2 line 23

“I think we need to be a lot quicker, I think we need to be more aware of asking that question, I don’t think enough people ask that and perhaps even when we do our assessments, perhaps that needs to be one of the questions on the assessment that we ask ‘can you read and write Ok’” Transcript 7 line 167-170

“If they’re not asked, its pretty key. {as simple as that} it is as simple as that. If you don’t ask you wouldn’t know maybe.” Transcript 6 line 99-101

"I like to sit and speak with people because through their terminology you can acknowledge and assess quite a lot, through their structure of sentences, through their social cues, pauses" Transcript 8 line 66-69

Utilising service users/experts by experience

"co-production is a good place to start, don't assume that we as an organisation know the best way to do things or to describe things for people with lived experience because we don't, we need to ask people" Transcript 6 line 207-210

"I always think it's nice if they are able to see other examples of people with similar issues" Transcript 1 line 198-199

Being creative

"you might even look to draw pictures, engage in art, there are other ways of finding out what people want but you do have to be a bit creative about it" Transcript 2 line 79-81

"Its about adapting your approach, with things like, if you've got situations like that someone's not going to be in the position to read and take on sort of information so its working with that person to identify how best are you actually going to be able to take this information on board" Transcript 3 line 119-123

"to put it in a nut shell what we do with people is to try and identify their needs and how they can have their needs met, so really to put it maybe too simply its about finding a way to do that, that works for someone that's in whichever sort of stage of their mental illness or having needs for their mental health coupled with the literacy difficulties, its just finding a way to still do that, tailored for that individual and their specific needs" Transcript 3 line 163-169

LTL Coding Summaries

Main theme: Service provision

Agreed Definition: Service structures are based on assumptions of literacy and in doing this we risk disempowering and causing potential iatrogenic harm to those with literacy difficulties.

Sub-Codes within Theme:	Transcripts which covered subtheme
Services assume good literacy skills when communicating	1,2,3,5,6,7,8,9
Unmet literacy needs means service users are more likely to disengage	1,2,3,4,6,7,8,9
Negative impact on care journey and outcomes (discharge, capacity, and medication)	2,4,5,7,8,9
Lack of agency for staff due to gaps in resources/training/materials	2,3,4,7,8,9
Unknown literacy difficulties a barrier to person-centred care (due to services not asking)	1,2,3,4,7,8,9
Iatrogenic harm resulting from service delivery	1,2,7,8

Summary/Interpretation of Data

Participants spoke about their experiences of how they perceived services to be set up in a way that assumes literacy capabilities. They reflected on how they felt that due to this assumption of literacy services are often not accessible to those who have extra needs. As a result of this they suggested that those with literacy difficulties are likely feeling disempowered by the service due to a sense of being done to rather than done with and may disengaged from the service. Participants also spoke about how these unmet needs and stigma experienced in services could result in iatrogenic harm.

Participants reflected on how services are set up, the systems and pathways, have the potential to have serious consequences for individuals with literacy difficulties. Participants gave examples from their own experience of this happening, including; inappropriate medication administration, prolonged discharges, and inappropriate capacity assessments.

Participants expressed their ideas that not all staff might feel confident working with literacy difficulties. They suggested that clinicians might feel a lack of agency due to a lack of knowledge/expertise working with individuals with literacy difficulties or not feeling they have the appropriate resources to support people with literacy needs. Some participants expressed that they felt there was a need as a service to think about reasonable adjustments we could be making for staff with literacy needs too.

Quotes for each subtheme

Services assume good literacy skills when communicating
"everything that we do is around words, sort of, a lot of it is around writing in the sense of you know if you've disengage from us and I send you an opt in letter in the post, if you can't read it, that's worthless, so you're not going to know that I'm trying to get hold of you because you've been referred and I need to make contact, everything is heavily reliant on letters or written communication so, I think there probably is more that we can do around that" Transcript 3 line 174-179

"and not making assumptions that everyone's going to find something that you think is really straight forward is going to be straightforward for them." Transcript 6 line 82-84

"you take it as, that everybody's been to school and stuff like that" Transcript 7 line 34-35

"I think sometimes we need to seek it out a little bit more, still as a professional I am reminded all the time that I tend to assume people can read and write" Transcript 8 line 45-47

Unmet literacy needs means service users are more likely to disengage
"at the moment that's all heavily based around literacy, which I think you run the risk of alienating the people who you know have difficulty with their literacy by doing it that way." Transcript 3 line 183-185

"you say you just need this leaflet or you just need this leaflet then eventually they're going to drop away, they're not going to be interested, it's not going to hold them, it's not going to do anything for them, and I think you know we stand a chance of losing people who as we know you know if you're at the lower end of the socioeconomic spectrum your health, your engagement with health and ability to access healthcare is negatively affected anyway and I think that you know that's where we're gunna end up, with people who really really need help choosing not to engage because they can't engage fully with it" Transcript 7 line 298-305

"I also think it's a massive barrier to engagement in service initial engagement a phonecall to give an appointment and then an appointment letter in easy read just in general for all client groups is probably quite successful as opposed to a letter without initial contact and spoken communication. And NHS letters can be quite threatening to people who don't understand" Transcript 8 line 54-59

Negative impact on care journey and outcomes (discharge, capacity, and medication)
"he was on a section and he wanted to appeal but he struggled to do that because of the sort of reading the information that was provided to him and at first he was too embarrassed to tell anyone that he couldn't read and write so he didn't seek any support he was just agreeing to things that maybe he wouldn't have agreed to if he had been able to read the information given." Transcript 4 line 5-10

"what was the most upsetting but was that I asked him if he knew the names of his medication and he didn't I asked him if he knew what his medication was for and he didn't I asked him if he was able to read the information leaflets that come in the boxes with the medication and he didn't understand, I asked him if he was taking his medication he said that he wasn't because he didn't know what time of day he was supposed to take them, and all of this had been presumed by the professionals involved" Transcript 8 line 226-232

"you know that could lead to all sorts of problems, can it, because you know you're handing people bags of drugs with the writing on the outside, you know how to follow taking your medication." Transcript 9 line 172-174

Lack of agency for staff due to gaps in resources/training/materials
"I think most people are pretty good about identifying if someone has a literacy difficulty but what do we then do about it" Transcript 2 line 206-207

"it's kind of difficult to know what else you could provide as such but I guess if we had more training then we would know more what we would need to provide" Transcript 4 line 64-66

"I think that's really the issue is yeah its resource availability so you know if you do uncover a problem you've got a solution for that difficulty and that problem and I think that's one of the big issues you don't want to ask a question and get the wrong answer do you and cause more issues" Transcript 7 line 208-212

Unknown literacy difficulties a barrier to person-centred care (due to services not asking)
"times someone's been given some information about mindfulness or autism and you go away and read that but actually you haven't checked to see whether they can read that first, so they might just stick it in the recycling bin for some people" Transcript 7 line 281-284

"Another sort of issue that we come up against is around signposting, every, a lot of it is around leaflets and giving people sort of information, and obviously if I cant, say if I cant read at all and you give me a leaflet unless I sort of make you aware that I cant read I'm not going to do anything with that leaflet." Transcript 3 line 9-14

"find some of the language is discriminatory stigmatising difficult to read difficult to understand" Transcript 6 line 220-221

Iatrogenic harm resulting from service delivery
"I'd imagine that the idea of homework is going to be you know have an association that is not particularly positive and put you back in the space of being a failure" Transcript 1 line 165-167

"I mean if you just launch straight in with that expectation, bombard them with literature which we do and we haven't checked then as we were saying earlier then you're potentially gunna negatively affect their mental health, possibly even you know affect engagement as well transcript" 7 line 292-295

"In absolute honesty I think there's a level of shame, I think because professionals presume and that shame kicks in even more" Transcript 8 line 143-145

“I think it’s because it’s a difference and it’s presumed so much that it becomes disempowering to them and they notice the absence and feel different for it maybe” Transcript 8 line 162-163

LTL Coding Summaries

Main theme: Social inequality

Agreed Definition: Society creates a stigma and discriminates against those with literacy difficulties.

Sub-Codes within Theme:	**Transcripts which covered subtheme**
Negative views of literacy difficulties in society placing people with literacy difficulties as outside the norm	1, 2, 3, 4, 7, 8, 9
Internalised fear of not being accepted or valued within society	All
Systemic barriers to achieving life goals for those with literacy difficulties (Social stigma)	2,3,7,8,9
Clinician's role in needing to challenge society's views	2,3,4,7,8

Summary/Interpretation of Data

Participants spoke at length about their perceptions of the negative views that society holds around literacy difficulties. They discussed how within society literacy is often taken for granted as a given skill and that society does not account for those that do not have literacy skills and thus there are many barriers to progress for those with literacy needs. Participants reflected on their views that this way that society operates is stigmatising for individuals with literacy needs and often leads to feelings of shame and embarrassment around literacy difficulties, which may be reinforced by the media. Participants spoke about how they felt that fear/shame/embarrassment may lead to individuals not being forthcoming about their literacy difficulties. Indeed, some participants shared experiences of those with literacy difficulties actively hiding or concealing their difficulties.

There was often a sense of participants trying to distance themselves from the stigmatising views of society, making it clear that they did not hold the views of society around the negative implications of having literacy difficulties. Some participants expressed their views that, as clinicians, we need to be actively challenging the stigma and barriers that these individuals may face.

Quotes for each subtheme

Negative views of literacy difficulties in society placing people with literacy difficulties as outside the norm

"societal pressures, you're out of the norm, yeah cultural aspects because from day one you're taught to read and write and it's something that should be able to do and it would be seen as, I think people are if you cant read or write you're deemed as like stupid" Transcript 2 line 84-86

"the majority, the majority of the time it would be cultural and societal pressures for why people hide it. And a worry or fear of being kind of unaccepted by people, others. Fear." Transcript 2 line 89-91

"fear that they gunna be perceived as stupid because they are dyslexic" Transcript 3 line 109-110

“I think it is just pure embarrassment, Like I say it’s that expectation that you should be able to read and write and that if you can't then you’re thick. It’s not the case at all, I think that’s I say I think it’s societies view, society judging and yeah not wanting, again not wanting to be seen to be erm lacking in skills in key areas.” Transcript 7 line 79-83

Internalised fear of not being accepted or valued within society

“more guarded about it and find it harder to accept and will cover up their abilities or lack of abilities, I think through, probably through fear” Transcript 2 line 30-33

“embarrassment of not wanting people to think that you know that you’re not intelligent or something along them lines, you’re just picking out that you’re different” Transcript 4 line 74-76

“I would suspect embarrassment is quite common and the way, I guess that people hide it, I think that that’s been a media portrayal that’s been a dramatic portrayal of people over the years that I think that people have felt embarrassed” Transcript 6 line 90-93

“societal expectation that people go to school, and that you read and write and that if you can’t read and write then there’s something wrong with you, you know and that there seems to be this misconception you know and you find those who struggle academically struggle to read and write have got massive skills in other areas, you know mechanical skills, artistic skills, you know but we as just society we I feel we judge and you know I was part of that I think.” Transcript 7 line 49-+55

Systemic barriers to achieving life goals for those with literacy difficulties (Social stigma)

“in some ways yes because of how the world has developed, I couldn’t imagine being able to do my job without being able to read and write, erm, yeah, I think the way that society has developed you do really need to be able to read and write, to achieve like stereotypically” Transcript 2 line 105-109

“but if you’re met with that over and over again and then you reside yourself to the fact that you’re never gunna understand and you can’t progress forward” Transcript 8 line 91-93

“because struggling with literacy is almost certainly going to hold you back, and if it holds you back, either with employment, training, education, relationships” Transcript 9 line 128-130

Clinicians role in needing to challenge societies views

“but there are other ways of, I think success can be defined in many ways and it might just not be based on your career basically.” Transcript 2 line 109-111

“I don’t agree, not at all. You know I think it's one of them awful things isn’t it, and we, it is just awful, and I think the more that is challenged the better, the more understanding people have over you know extra learning needs or however you want to put it then the less that stigmas going to be around, I think a lot of stigma comes from a lack of knowledge on their behalf, that they just don’t know enough about it.” Transcript 4 line 80-85

"I think with like stigma and that fear or anything it is one of those things you have to run through and sort of smash, cause actually one of the people in the XXX who is dyslexic is probably the best person in the team" Transcript 3 line 95-98

"point I'm very blunt I would literally get the grounds on a governance meeting I'd get the spotlight and say how many people here can you raise your hand how many people here can tell me if they've considered that the information they've shared with their patients is understandable for that individual I really would call them straight out and then I'd talk about statistics I'd bring in some decent research statistics and say this is what we're up against if this is the population of XX we need to be looking at that actually 30% of our patient group may be having these difficulties is it something that we're considering here's what we need to be doing why aren't we doing it" Transcript 8 line 395-404

Appendix O

Analysis steps suggested by Gale et al. (2013)

Stage 1: Transcription. Interviews should have an audio recording and verbatim transcription. The transcript does not need to included all of the conventions of a dialogue transcription as the primary interest is the content of the interviews. Transcripts should include adequate line spacing and large margins to allow for note taking and coding in the analysis process.

Stage 2: Familiarisation with the interview. Those involved in analysis should familiarise themselves with the entire interview using the transcript or audio recording. Notes can by made in the margin whilst familiarising with the transcript. This stag is particularly important where those doing the data analysis were not involved in conducting the interview.

Stage 3: Coding. Once familiar with the transcript the research should read the transcript one line at a time using the margin to apply a paraphrase or label that describes what they have interpreted in each passage. The first few transcripts should be coded by at least two researchers where possible.

Stage 4: Developing a working analytical framework. Once the first few transcripts have been coded all researchers should meet together to compare the labels they have and agree on a set of codes to use when analysing subsequent transcripts. A working analytic framework is then formed by grouping codes together in to categories and defining these categories. A ‘other’ code can be used to capture new data which doesn’t fit these initial codes. This analytical framework will therefore likely evolve until all transcripts have been coded.

Stage 5: Applying the analytical framework. The analytical framework is then applied to each subsequent transcript.

Stage 6: Charting data into the framework matrix. The data from all transcripts is then charted into a spreadsheet matrix. The data is summariser from each transcript into categories. This matrix should include quotes which illustrate the codes.

Stage 7: Interpreting the data. Over the process of applying the analytical framework and creating the matrix characteristics of the codes and differences between the data are mapped out. Gradually through this process connections within and between the codes can be explored and interpreted.