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**Service user experiences of accessing support for psychosis in rural Highlands and the potential role of Smartphone technology: a qualitative exploration**

**And Clinical Research Portfolio**


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**BSc (Hons) Psychology**

**MSc Psychological Therapy in Primary Care**


Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

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Chapter One: Systematic Review

**The association between mental health stigma and help-seeking in rural populations: a systematic review.**

Submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (DClinPsy)

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**Abstract**

**Background & Objective:** Stigma may be a key factor in deterring individuals from seeking help from mental health services. As rural communities have been found to have higher levels of stigma, it is important to review if this has a meaningful impact on help-seeking. The aim of this study was to explore the association between mental health stigma and help-seeking in rural populations.

**Methods:** A systematic search was conducted using Medline, EMBASE, PsychINFO and CINAHL using derivations of mental health, stigma and help-seeking. Methodological quality was assessed using the AXIS rating tool.

**Results:** In total, 11 studies were identified for review. Nine studies explored the impact of perceived public stigma and help-seeking, with seven finding no association, and two finding that increased public stigma predicted a decrease in help-seeking intentions. One study found increased self-stigma predicted negative help-seeking attitudes and intentions. Five studies explored the role of treatment stigma and found mixed results, with three finding a significant association and two not. The methodological quality varied, with a number of studies having multiple potential sources of bias. There was significant heterogeneity in measures and definitions of rurality.

**Conclusions:** A number of studies reported the presence of stigma within rural communities but this was not consistently associated with help-seeking. However, the wide range of definitions of rurality, and inconsistencies in measures of stigma and help-seeking, make clear conclusions difficult. Nonetheless, given the wider negative consequences of stigma on an individual's self-esteem and quality of life, more methodologically robust research is required to clarify the need for targeted support in rural communities.

*Key Words: systematic review; mental health; rural; stigma; help-seeking.*

**The association between mental health stigma and help-seeking in rural populations:**
**a systematic review**

## Introduction

In the United Kingdom (UK) it is estimated that as few as a quarter of adults with a common mental health issue access treatment (Department of Health, 2014). A delay or lack of access to mental health support is associated with worsening mental health and increased risk of suicide (Altamura et al., 2010). With clear negative consequences of reduced access, it is important to explore possible factors that influence this.

The term rurality is often utilised in health research and policy without a clear universal definition (Hart, Larson & Lishner, 2005). This is partly due to the challenge of defining a construct that has diverse spatial, economical and sociological characteristics that can vary across cultures and communities. Stamm et al. (2001) noted that there is no approach to defining rurality that is wholly satisfactory, as any one definition may fail to consider a number of important factors. The only thread that may connect definitions of rurality is their lower population densities (Cordes, 1990).

Rural experience may impact on help-seeking; research has demonstrated that even when services are present, individuals residing in rural regions display lower help-seeking (Caldwell et al., 2004). Additionally, individuals living in rural communities experience higher rates of suicide (Hirsch & Cukrowicz, 2007) and increased mental and physical health issues (Hartley, 2004). This demonstrates the potential disparities between rural and urban experiences of health and access to support. Research has highlighted the unique set of practical barriers that may impede access to rural health services, including a lack of public transport, poor availability of broadband internet, and difficulties employing and retaining trained professionals (Douthit et al., 2015). These structural barriers can affect accessibility and perceived quality of health services (Parr, Philo & Burns, 2004). There are also attitudinal barriers, such as stoicism, self-reliance and stigma, which have been found to be more prominent in rural communities (Jackson et al., 2007). It is thought that negative attitudes are compounded by the smaller size and lack of anonymity associated with rural communities (Aisbett et al., 2007).

Stigma has been defined as a phenomenon whereby an "attribute that is deeply discrediting" results in the disqualification "from full social acceptance" (Goffman, 1963, p. 9). Link and Phelan (2001) conceptualised stigma to include key components and processes that occur "when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allow the components of stigma to unfold" (p. 363). This definition is important as it moves the source of stigma from the person to those who have power to label and discriminate.

Mental health stigma can be defined in terms of public and self-stigma (Corrigon, 2004). Public stigma relates to the negative labels, discrimination and attitudes that are held and perpetuated by larger groups of people within society; self-stigma occurs when an individual internalises and endorses negative societal attitudes and stereotypes, and applies these to themselves or to people with mental health issues more generally. Self-stigma can lead to expected discrimination and the belief that they are a devalued member of society (Ritsher & Phelan, 2004). On a more macro level, institutional stigma describes the private and public structures within societies, and the values and policies they hold, that limit the opportunities and rights of people with mental health issues (Corrigon, Markowitz & Watson, 2004). A further relevant aspect of mental health stigma relates to treatment stigma which is defined as negative attitudes associated with seeking and/or receiving treatment for mental ill health (Clement et al., 2015). There are various socio-demographic factors that have been found to be associated with increased mental health stigma, including being male and older (Stewart, Jameson & Curtin, 2015; Vogel et al., 2007). Certain psychiatric diagnoses are also associated with increased levels of stigma, particularly psychosis (Wood et al., 2014).

There have been two previous comprehensive meta-analyses on the impact of stigma on help-seeking. Schnyder et al. (2017) found that participants' *own* negative attitudes towards help-seeking (OR = 0.80, 95% CI 0.73–0.88), and their stigmatising attitudes towards people with mental illness (OR = 0.82, 95% CI 0.69–0.98), were associated with less active help-seeking. Neither public nor self-stigma was significantly associated with help-seeking. Clement et al. (2015) found an overall small-moderate effect size of stigma on help-seeking, with treatment and self-stigma being most often associated with reduced help-seeking.

**Rationale**

Although, two meta-analyses found an association between stigma and help-seeking, Clement et al. (2015) and Schnyder et al. (2017) did not explore rurality in their subgroup analyses. To date there has been no systematic review on the impact of stigma on help-seeking within a rural context. Given that research has demonstrated that there are increased levels of stigma in rural areas, it is important to establish if stigma has a clinically meaningful effect on help-seeking (Hammer, Vogel & Heimerdinger-Edwards, 2013; Stewart et al., 2015). This understanding will help to establish the need and approach for initiatives targeting stigma within rural communities.

**Objectives**

1. To systematically review the literature on the impact of stigma on help-seeking within a rural context.
2. To explore how rurality and stigma are being defined and measured within this body of literature.

**Method**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was utilised in guiding this systematic review. An initial scoping exercise was completed to identify relevant research in the area to assess utility and feasibility of the review.

The electronic systematic searches were undertaken on MEDLINE, EMBASE, PsychINFO and CINHAL in April 2019. Search terms were developed from the literature with appropriate adaptations made for the different databases (see Appendix 1.2). A University Librarian was consulted for assistance in refining search terms. Variations and synonyms of the following terms were used:

1) Mental health or mental disorders or mental disease

And

2) Stigma or discrimination or prejudice or attitudes

And

3) Help-seeking or health care utilisation or barriers or delay

Terms relating to rurality were not included as this may have reduced the sensitivity of the search and missed papers that completed rural sub-group analysis but did not report it in the title or abstract. A citation search of two key research papers in the area (Rost, Smith & Taylor 1993; Komiti, Judd & Jackson, 2006) were carried out on Scopus to identify any additional papers on the area and increase the sensitivity of searches.

Studies identified through the above search strategy were reviewed against the inclusion/exclusion criteria. Studies were gathered in Endnote and duplicates removed. Initially, the titles of the studies were reviewed and excluded if they indicated the study was not relevant. The abstract of the papers that remained were then reviewed. The abstracts that indicated the study may be relevant were then reviewed in full.

**Inclusion criteria**

The following inclusion criteria were utilised:

- Published and un-published quantitative studies written in English language;
- Adult (16+) clinical and/or non-clinical samples;
- Any type or aspect of mental health stigma that is assessed by a measure and/or item/s;

- Help-seeking measured through actual contact (current or past) and/or help-seeking attitudes and/or intentions with formal and/or informal sources of support;
- A statistical association was made between stigma and help-seeking using regression analysis;
- A rural population (loosely defined as individuals not living in cities) was included in the analysis.

**Exclusion criteria**

The following exclusion criteria were utilised:

- Qualitative, intervention and/or single case studies;
- Stigma relating to other social groups;
- Help-seeking for another person or a physical/neurological condition.

**Methodological quality**

Downes et al. (2016) developed a critical appraisal tool that addresses study design and reporting quality, as well as the risk of bias, in cross-sectional studies: the Appraisal tool for Cross-Sectional Studies (AXIS) (see Appendix 1.3). This consists of 20 components: each study in this systematic review was rated yes, no, or unsure for each component.

To ensure inter-rater reliability in quality ratings, an independent rater reviewed three purposively selected studies that were of varying quality. A purposive sample was utilised to ensure that the independent rater reviewed studies of differing quality that reflected the overall body of research. There were high-levels of consistency between ratings and if there were any discrepancies in ratings, discussions were held until agreement was achieved.

## Results

The process of the systematic review is outlined in Figure 1. A total of 11 studies were included in the review. The studies are summarised in Table 1.

**Figure 1: Prisma Flow Diagram** (Moher et al., 2009)
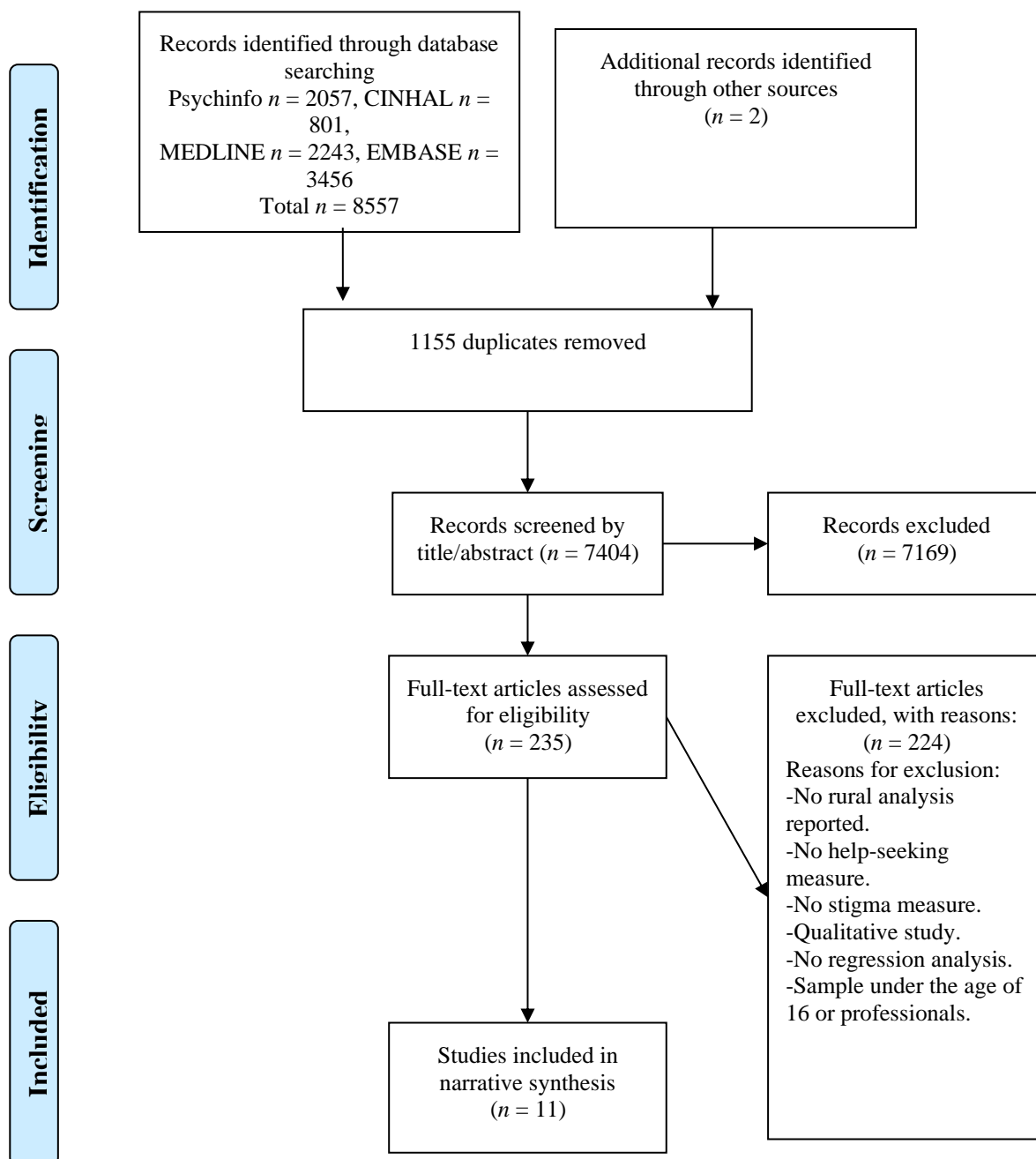
**Table 1: Summary of included studies**

| Article & location | Participants & rural definition | Stigma variable | Help-seeking variable | Regression type & key results |
|---|---|---|---|---|
| **Deen, Bridges, McGahan & Andrews (2012)**<br><br>USA<br>Peer-reviewed | $n$ = 99<br><br>Female: 56 (57%)<br>Mean age: 45<br><br>Living in a town of less than 5,500 & living at least 30 minutes from a city of 30,000 or more. | Single agree/disagree statement: "My friends & family will think I am crazy if I see a counsellor or therapist." | Life-time use of psychologist, psychiatrist, social worker or counsellor for an emotional or substance-use related disorder. | Multiple Logistic Regression:<br><br>45% of the sample had sought specialist professional support.<br><br>Stigma (OR = 0.45) did not significantly distinguish between participants who sought specialty mental health support and those who did not. |
| **D'Cunha (2014)**<br><br>USA<br><br>Thesis | $n$ = 203<br><br>Female: 153 (75%)<br>Mean age: 36<br><br>Rural and urbanised counties within a rural Midwestern state. The US Census Bureau's (2010) definition of rurality as an area with less than 25,000 was used. | Perceptions of Stigmatisation by Others for Seeking Help (PSOSH).<br><br>Self-Stigma of Seeking Help Scale (SSOSH). | Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS).<br><br>Likelihood of Seeking Help Scale (intentions measure developed during the study). | Stepwise Hierarchical Regression:<br><br>Increased self-stigma significantly predicted negative attitudes towards help-seeking ($\beta$ = -.51) and reduced intentions ($\beta$ = -.05), accounting for 41% of variance in attitudes and 11% for intentions.<br><br>Public stigma did not significantly predict attitudes or intentions.<br><br>Attitudes significantly predicted intentions ($\beta$ = .23).<br><br>Mental health literacy did not significantly moderate the relationship between private stigma and help-seeking. |

| Green, Hunt & Stain (2012)  Australia  Peer-reviewed | *n* =124  Female: 88 (71%) Mean age: 53  Participants had an anxiety or depressive disorder according to CIDI.  Remoteness defined using ARIA+ index scores (Australian Statistical Geography Standard, 2011)  Inner regional: *n*= 60 Outer regional: *n*=50 Remote & very remote: *n*=14 | Perceived Stigma Scale (PSS). | Treatment delay used for help-seeking variable.  For participants reporting past professional contact, treatment delay was measured by subtracting self-reported age of onset from age of first professional contact.  For participants reporting no previous professional contact, treatment delay was measured by subtracting self-reported age of onset from current age. | Hierarchical Logistic Regression:  Perceived stigma did not significantly predict delay in help-seeking.  Increased rurality did not significantly predict longer delay.  PSS mean of 41.63 (SD 6.47). |
| --- | --- | --- | --- | --- |
| Herzberg (2013)  USA  Thesis | *n* = 106  Female: 88 (83%) Mean age: 54  Community of approximately 7000 people and 35 mile radius from surrounding counties. | Perceived Stigma Scale (PSS). | Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS). | Simultaneous Linear Regression:  Perceived stigma did not significantly predict attitudes towards help-seeking.  Levels of stigma were not correlated with levels of rurality.  PSS mean: 39 (6.38). |

| | | | | |
|---|---|---|---|---|
| **Hoyt, Conger & Valde (1997)**<br><br>USA<br><br>Peer-reviewed | *n* = 1487<br><br>Female: 952 (64%)<br>Mean age: Not reported<br><br>6 categories of rurality:<br>-Farm households: 10%<br>-Rural non-farm households: 8.5%<br>-Rural villages (under 2,500): 15.4%<br>-Small towns (2,500 – 9,999): 14.9%<br>-Small cities (9,999 – 49,999): 14.2%<br>-Rural population centre (50,000+): 36.9% | Two Likert scale items: One representing the degree of embarrassment if people found out they were seeking professional help for mental health, and the other representing how likely they felt it would be for others in their community to find out they were getting professional help. The average across these two represented the stigma variable. The variable has a potential range of 1 – 16, with higher values representing increased stigma. | Willingness to seek help assessed by two Likert scale items: One is representing likelihood of going for help with a "serious emotional problem" and the other representing how willing they were to talk to a professional about "personal problems".<br><br>The variable was computed as a mean response across the two. | Multiple Logistic Regression:<br><br>People in the most rural places were significantly (p<.01) more likely to hold stigmatised attitudes towards mental health. The magnitude of the differences in levels of stigma ranged from a contrast of *b*= 0.89 for small cities and *b*=2.28 for rural villages.<br><br>Stigma towards mental health service use was associated with willingness to seek help from services in the future in the overall sample (*b* = -0.02, p<.001). When stigma was added to the model, the above effect of rurality becomes non-significant.<br><br>Mean stigma score: 8.10 (SD = 3.42) |
| **Judd et al. (2006)\***<br><br>Australia<br><br>Peer-reviewed | *n* = 467<br><br>Female: 271 (58%)<br>Mean age: 57<br><br>People living on farms or small towns (<1,000). | Perceived Stigma Scale (PSS).<br><br>Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS). | "Have you ever sought help from a GP and/or mental health professional for a mental health issue?" | Hierarchical Logistic Regression:<br><br>Perceived stigma and attitudes towards help-seeking did not significantly predict help-seeking from a professional.<br><br>PSS mean of 40.10 (SD 4.96) |

| | | | | |
|---|---|---|---|---|
| **Komiti et al. (2006)***<br><br>Australia<br><br>Peer-reviewed | $n = 300$<br><br>Female: 148 (49%)<br>Mean age: 57<br><br>Rural defined as a large regional centre (population size >20,000), medium sized rural towns (populations 1,000–20,000), and small rural towns (populations < 1,000). | Perceived Stigma Scale (PSS).<br><br>Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS). | "Have you ever sought help from a GP for psychological or mental health problems?" | Simultaneous Logistic Regression:<br><br>Perceived stigma did not significantly predict help-seeking from a GP.<br><br>Attitudes towards help-seeking did predict help seeking from a GP (Exp($B$) = 1.06, CI: 1.01-1.11).<br><br>Perceived stigma did not significantly differ across population sizes.<br><br>PSS mean of 42.18 (SD 6.28) |
| **Rost et al. (1993)**<br><br>USA<br><br>Peer-reviewed | $n = 103$<br><br>Female: 72 (70%)<br>Mean age: 38<br><br>Previous self-reported depression:<br>Rural $n$=48<br>Urban $n$=55<br><br>Urban defined as a metropolitan statistical area (MSA) - a county that has at least one urban core area of at | 14 item Semantic Differential Scale (SDS) measured labelling linked with depression. Completed scale in response to a vignette about an individual experiencing depression twice.<br><br>First completion of the scale related to labelling the character's mental health & the second time related to labelling the | Measured by asking participants if they had ever sought help from a physician or community mental health centre for depression or sadness. | Hierarchical Logistic Regression:<br><br>Increased negative labelleing related to treatment predicted reduced likelihood of actual help-seeking in rural residence with history of depression ($B$=1.16, X2=4.02, p<0.04). This wasn't the case for urban participants.<br><br>Labelling related to the character's mental health was not significantly related to use of care for either rural or urban participants. |

| | least 50,000. Any non-MSA surrounding county classified as rural. | character in response to them seeking treatment. Treatment stigma variable measured by subtracting first scale from the second. | | |
|---|---|---|---|---|
| **Smith, Peck & McGovern (2004)**<br><br>USA<br><br>Peer-reviewed | $n = 393$<br><br>Female: 153 (39%)<br>Mean age: 54<br><br>Recruited from rural counties with populations between 4,170 and 24,977. | Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS). | Participants were asked if they had ever seen a professional counsellor, psychologist, psychiatrist, social worker, minister or family physician for a mental health concern.<br><br>They were also asked whether they thought they would seek treatment in the future. | Multiple Logistic Regression:<br><br>The attitudes scale did significantly predict past help-seeking ($b = -.079$) and future intentions ($b = -.019$). |
| **Wrigley, Jackson, Judd & Komiti (2005)**<br><br>Australia<br><br>Peer-reviewed | $n = 142$<br><br>Female: 92 (65%)<br>Mean age: Not reported<br><br>Recruited from a rural community with a population fewer than 10,000. | Perceived Stigma Scale (PSS).<br><br>Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS). | "Would you feel comfortable discussing mental health issues with your GP?" | Hierarchical Logistic Regression:<br><br>Perceived stigma and attitudes towards treatment were not significantly predictive of intentions to seek help from a GP.<br><br>Reduced stigma was predictive of more positive attitudes towards treatment ($\beta=0.43$, $p<.05$).<br><br>PSS mean of 37.51 (4.93) |

| Yu et al. 2015  China  Peer-reviewed | n = 2052  Female: 1149 (56%) Median age: 42  Two "rural" villages within Liuyang County. Definition of these not provided. | Perceived Devaluation-Discrimination Questionnaire (PDD). | Participants asked "If you had severe psychological or mental health problems, would you seek help from a professional source?" | Multiple Logistic Regression  Perceived stigma was not significantly associated with help-seeking intentions. |
|---|---|---|---|---|

*Participants recruited from a pool of participants (n= 1,238) from a previous study who agreed to further contact regarding research (Murray et al., 2005).

### Study Characteristics

**Sample**

Two studies included clinical samples (Green et al., 2012; Rost, et al., 1993) and the other nine studies recruited from general populations. A total of 5,342 participants were included across the eleven studies. The overall sample comprised 3,222 (60%) females. Six studies were conducted in the United States of America (USA), four in Australia and one in China. Judd et al. (2006) and Komiti et al. (2006) recruited from a large sample (n= 1,238) of participants from a previous study who agreed to further contact regarding research (Murray et al., 2004). The two studies were included independently due to the large sample pool of the original study but it should be noted that there is a possibility of shared participants.

**Design of studies**

All studies were observational and cross-sectional in design. All studies utilised self-report methodologies to assess stigma and help-seeking. All studies were retrospective in nature, with none utilising longitudinal designs.

**Help-seeking**

For the help-seeking outcome variable, four studies measured self-reported actual help-seeking from professionals, including mental health specialists and general practitioners. One study measured help-seeking delay by subtracting reported onset of symptoms from self-reported date of accessing support (or current age if no previous help-seeking was reported). Five studies measured help-seeking attitudes and/or intentions. One study measured both intentions and historical actual help-seeking.

### Findings

As the studies measured various types of stigma, findings are generally divided into perceived public stigma, self-stigma and treatment-seeking stigma. The findings are presented in the context of actual or intended help-seeking.

**Perceived public stigma**

Five studies used the Perceived Stigma Scale (PSS) to measure public stigma. Three of these studies found that public stigma did not significantly predict actual or delayed help-seeking (Judd et al., 2006; Komiti et al., 2006; Green et al., 2013). The other two studies also found that public stigma did not significantly predict attitudes towards help-seeking. (Wrigley et al., 2005: Herzberg, 2013). However, Wrigley et al. (2005) did find that increased public stigma did significantly predict reduced help-seeking intentions ($\beta$=.43).

A further four studies used other measures to assess public stigma. Two studies found that public stigma, as measured by the Perceived Devaluation-Discrimination Questionnaire (PDD) and Perceptions of Stigmatisation by Others for Seeking Help (PSOSH), did not significantly predict help-seeking attitudes or intentions (D'Cunha 2014; Yu et al., 2015). Studies utilising single items found that increased public stigma did not predict actual help-seeking (Deen et al., 2012) but did significantly predict reduced intentions to seek support ($\beta$= -.11) (Hoyt et al., 1997).

**Self-stigma**

Only one study assessed the role of self-stigma on help-seeking using the Self-Stigma of Seeking Help Scale (SSOSH). D'Cunha (2014) found that increased self-stigma significantly predicted increased negative attitudes ($\beta$=-.51) and reduced intentions ($\beta$=-.05) towards help-seeking. Self-stigma was reported to account for 41% of the variance in help-seeking attitudes and 11% in help-seeking intentions.

**Treatment-related stigma**

Five studies explored the relationship between treatment-related stigma and/or attitudes, and help-seeking. Four studies utilised the Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS) as the predictor variable. Two studies found that more positive attitudes towards help-seeking significantly predicted increased actual help-seeking ($\beta$=.079 & $\beta$=1.06) (Smith et al., 2004; Komiti et al., 2006) but one study did not (Judd et al., 2006). Smith et al. (2004) also found that more positive attitudes towards help-seeking significantly predicted increased intentions to seek help ($\beta$=-.019) but Wrigley et al. (2005) did not. Rost et al. (1993) found the more negative the labelling associated with treatment seeking, the less likely rural residents with histories of depressive symptoms were to have sought professional help ($\beta$ =1.16).

**Table 2: Overview of stigma measures**

| Stigma measure | Brief overview | Psychometric properties from original study | Psychometric properties from reviewed studies |
|---|---|---|---|
| Perceived Stigma Scale (PSS) Wrigley et al. (2005) | 16 item scale. Developed from PDD scale with the addition of four items to gauge the responses of people within the local community towards someone with a mental illness. | Good internal reliability ($\alpha = 0.80$). Wrigley et al. (2005). | Judd et al. (2006): Not reported Komiti et al. (2006): $\alpha = 0.84$ Green et al. (2012): $\alpha = 0.89$ |
| Perceived Devaluation-Discrimination Questionnaire (PDD) Link et al. (1991) | 12 item scale developed to assess the extent to which a person believes that other people will devalue or discriminate against someone with a mental illness. | Good internal reliability ($\alpha = .78$). Link et al. (1991). | Yu et al., (2015): $\alpha = 0.67$ |
| Perceptions of Stigmatisation by Others for Seeking Help (PSOSH). Vogel et al. (2006) | 5 item scale developed to capture aspects of perceived public stigma for seeking help for mental health issues. | Good internal reliability ($\alpha = 0.91$) and test-retest reliability (0.82). Vogel et al. (2006) | D'Cunha (2014): $\alpha = 0.92$ |
| Self-Stigma of Seeking Help Scale (SSOSH) Vogel et al. (2006) | 10 item scale that measures different aspects of internalised stigma related to seeking help (e.g. "If I went to a therapist, I would be less satisfied with myself"). | Good internal reliability ($\alpha = 0.86 - 0.91$) and test-retest reliability reported at 0.72. Vogel et al. (2006). | D'Cunha (2014): $\alpha = 0.85$ |
| Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS) Fisher & Turner (1970) | 29 item scale that measures attitudes towards help-seeking. One aspect of this is stigma-tolerance, with low stigma tolerance indicating higher stigma towards help-seeking. | Test-retest reliability ranged from .73 to .89 (Fischer & Turner, 1970). | Judd et al., (2006): Not reported Wrigley et al. (2005): $\alpha = 0.80$. Komiti et al. (2006): $\alpha = 0.85$. Smith et al. (2004): $\alpha = 0.88$ |
| Semantic Differential Scale Rost et al. (1993) | 14 item scale to characterise how other people would label a character in a vignette if they found out they were having emotional problems and if they sought professional support. Various Likert scales (e.g. strong - weak) are presented. | Good internal reliability when measuring the labelling of the person in a vignette with an emotional problem ($\alpha = 0.81$) and for seeking professional support ($\alpha = 0.71$) (Rost et al., 1993) | |

**Methodological review of studies**

Strengths and weaknesses of the studies will be outlined using key aspects of the quality framework in the AXIS tool (Downes et al., 2016). Overall, the quality varied among the studies, and the majority had at least some form of potential bias. All studies adopted an appropriate cross-sectional design. All studies except two (Rost et al., 1993; Hoyt et al., 1997) outlined a clear procedure that included both methodology and analysis. Whilst most studies had relatively large sample sizes, only Herzberg (2013) reported power calculation. Four studies (Rost et al., 1993; Deen 2012; Herzberg 2013; D'Cunha 2014) utilised convenience sampling methods (e.g. people attending a rural grocery store) that are unlikely to be representative of the wider population group.

One thing that was an issue among studies was either low response rates (Smith et al., 2004; Wrigley et al., 2005; Deen et al., 2012; Green et al., 2012), not reporting response rates (Rost et al., 1993; D'Cunha 2014; Yu et al., 2015) and no further exploration of demographic differences which allows little ability to see whether responders are representative. Komiti et al. (2006) found responders were significantly older and Judd et al. (2006) found responders were significantly more likely to be male. These significant differences highlight the importance of investigating and reporting these details to identify potential bias. Eight of the studies utilised a previously published and/or psychometrically assessed tool to measure stigma and/or attitudes towards treatment. Deen et al. (2012) and Hoyt et al. (1997) utilised a single or two item measure of stigma that had not been psychometrically validated or previously piloted. The majority of studies utilised a single item question for help-seeking that had not been psychometrically assessed and therefore may not be a valid method to assess this variable. All studies except Hoyt et al. (1997) and Rost et al. (1993) reported obtaining ethical approval and/or informed consent. All studies made appropriate conclusions and outlined possible limitations.

The definitions of rurality included across the studies varied significantly (see Appendix 1.3 for full overview). Deen et al. (2012) provided a good synthesis of research and justification for the criteria of a population with fewer than 5,500 that is 30 minutes away from a city of over 30,000. This definition captured a low population density and remoteness from urbanised areas that are likely key components of rural experience. A number of studies utilised official systems or definitions appropriate to the country of the study. This seemed

an appropriate and objective way to define rurality; however, some studies still included aspects that may not be representative of rurality. For example, a number of the studies conducted in Australia included 'inner regional' or 'large regional' populations that only have some restrictions to accessibility to some goods and services within the community (Wrigley et al., 2005; Judd et al., 2006; Komiti et al., 2006; Green et al., 2012). The system used in these four studies only measured remoteness and did not necessarily include other key factors of rurality. Hoyt et al. (1997) included areas of over 50,000 people in their rural definition which again may not be accurate of rurality. Rost et al. (1993) defined rural and urban using a distinction in line with the US census; however, they did not provide a clear overview of population density or remoteness of the 'rural' counties included. In one study, half of the sample self-rated their location as rural, urban or metropolitan without the researcher providing participants with guidance of what each constitutes (D'Cunha, 2014). Yu et al. (2015) named the rural villages that were included but did not provide any details about how they classified them as rural. The overall quality ratings can be found in Appendix 1.4.

**Discussion**

This review identified eleven studies that investigated the association between mental health stigma and help-seeking in a rural context. The aim of this review was to provide a narrative synthesis of the literature on the impact of stigma on help-seeking in rural populations. The review also aimed to establish how stigma and rurality were measured and defined within the body of literature.

Nine studies explored the impact of perceived public stigma on help-seeking. The majority found that there was no significant association between perceived public stigma and help-seeking. Only two studies found a significant association between increased public stigma and negative help-seeking attitudes and reduced intentions (Hoyt, et al., 1997; Wrigley et al., 2005). However, both of these studies had significant methodological problems, including very poor response rates in Wrigley et al. (2005), and the use of a non-validated, single item measure of stigma in Hoyt et al. (1997). These methodological problems mean these results need to be interpreted with strict caution. Overall, this review found no evidence that measures of public stigma were associated with actual help-seeking, and very limited, low quality evidence related to help-seeking intentions in rural populations. This is in line with a previous comprehensive meta-analysis that found perceived public stigma was not associated with actual help-seeking (Schnyder et al., 2017).

D'Cunha (2014) found that self-stigma was significantly associated with help-seeking attitudes and intentions but did not measure actual help-seeking. This study also had methodological weaknesses, including the use of a convenience sample and a lack of an objective measure of rurality in half the sample, which should be considered when interpreting this result. This preliminary finding is in line with previous reviews that found a significant association between self-stigma and help-seeking (Clement et al., 2015). Vogel et al.'s (2007) model of stigma suggests that the link between perceived public stigma and willingness to seek mental health support is mediated by self-stigma.

This review found mixed results on the impact of attitudes and stigma related to seeking treatment. Komiti et al. (2006), Smith et al. (2004) and Rost et al. (1993) found negative attitudes and increased stigma towards treatment were associated with reduced actual help-seeking. Komiti et al. (2006) was one of the methodologically better studies but Smith et al. (2004) and Rost et al. (1993) had significant methodological problems (e.g. very low

response rates and the inclusion of city populations) that should be considered when interpreting their results. Two studies did not find a significant association between treatment seeking attitudes and actual or intended help-seeking (Wrigley et al., 2005; Judd et al., 2006). Two previous meta-analyses both found that increased stigma towards treatment was significantly associated with reduced help-seeking (Clement et al., 2015; Schnyder et al., 2017). Given the mixed results identified, and the significant methodological issues within the literature, it is unclear if this association extends to rural communities.

There was significant variability in the quality of reported definitions of rurality. The majority of these definitions focused on a single factor, such as remoteness, and did not consider other important aspects. Given that rurality is a complex multidimensional construct, these simplified definitions may lack validity (Kule, 2008). Furthermore, a number of studies included populations (e.g. small cities) that were more representative of urbanicity than rurality. With a wide range of definitions, of varying quality, caution must be exercised when generalising the findings of the included studies to wider rural communities.

**Strengths and limitations**

This systematic review is the first, to the author's knowledge, to assimilate quantitative studies that evaluate the association between stigma and help-seeking in rural populations. The review included a broad search strategy of published and unpublished literature to increase sensitivity. A limitation of this review is the inclusion of a number of studies that utilised measures of help-seeking intentions and attitudes rather than actual help-seeking. Whilst the Theory of Planned Behaviour (Ajzen, 1991) suggests intentions correlate with behaviour, in practice people may endorse help-seeking (Coppens et al., 2013) at higher rates than actual help-seeking (Wang et al., 2007). This questions the validity of help-seeking measures that purely assess intentions and attitudes. A significant limitation of this review is the limited ability to make comparisons across the research, because of the varying definitions of rurality used across studies. As a result the conclusions and recommendations for wider rural populations are limited in their generalisability, which is a significant issue for all research in this area. This is a reflection of the varying political, geographical and cultural contexts of the countries in which studies were completed. All studies within the review were cross-sectional in nature which means causal relationship cannot be established.

Given the significant disparities between studies and the limited amount of research related to the review's objectives, it may be questioned whether the body of literature was developed enough for a thorough systematic review. This likely limited the ability to reach definitive conclusions to the questions this review aimed to answer. With this in mind, further research, particularly in the United Kingdom, is required to establish the impact of stigma on help-seeking in rural communities. This research should utilise more robust and consistent methodologies to make comparisons and wider conclusions possible. This will require standardised and psychometrically sound measurements of the various types of stigma and help-seeking. A clear, valid and more universally accepted definition of rurality, which captures the fundamental aspects of rural experience, will allow for clearer conclusions and recommendations. This could be achieved by utilising qualitative research to identify the core aspects of rural experience. This lived experience, alongside more robust objective measures (e.g. population density and remoteness), may result in a more valid definition and overview of rurality.

**Future research**

There is a paucity of high quality research on the experiences of public, treatment and self-stigma in the context of rural settings and its impact on intentions to or actually seek help. Given higher suicide rates (Hirsch & Cukrowicz, 2007) and increased mental health issues (Hartley, 2004) in rural areas, it is important that future research seeks to understand the potential negative impact stigma has on help-seeking. Qualitative research into the lived experiences of mental health stigma, discrimination and help-seeking in rural areas could help develop a better theoretical understanding of these processes within this population group. This may help build theoretical models that could guide future research and the development of measures that are tailored to rural experiences. It is crucial that a meaningful model of rural experience exists in order to guide appropriate adaptations to public health policy.

Future studies should make direct comparisons between associations in rural and urban communities to establish if there are significant and meaningful differences, but this would require more consistent use of accepted definitions of rurality. More prospective studies of stigma and help-seeking in rural communities are required to overcome the issue of reciprocal or reversed causation in cross-sectional studies. Furthermore, as all the studies

focussed on the initial access into support, it is important to explore the contributions of stigma on disengagement by those in contact with services. Given the limited studies on the role of self-stigma, further research is required to establish if this has a meaningful impact on help-seeking in rural contexts. It would also be beneficial to explore institutional stigma within rural mental health services to establish what constitutes stigmatising and discriminatory practice and policies, and the impact this has on help-seeking.

**Clinical implications**

Whilst some included studies found that stigma was present in rural populations, there were mixed findings on the whether increased rurality predicted increased levels of stigma. Other studies, however, have found an association between rurality and increased stigma that suggests rural areas may need targeted support (Hammer et al., 2013; Stewart et al., 2015). Despite the mixed impact of stigma on help-seeking, there are other negative consequences associated with experiencing stigma, including increased hopelessness, poorer self-esteem, reduced mastery and self-efficacy, and decreased quality of life (Livingston & Boyd, 2010). Given the negative impact of stigma, it is important to explore methods which may help to reduce negative perceptions of mental health. A number of programs that aim to reduce stigma and discrimination associated with mental illness have been launched worldwide (Corrigon, 2012). Stigma and discrimination reducing programmes focusing on education, training, media campaigns, contact with individuals with mental health difficulties, or a combination of these, have shown promise (Collins et al., 2013). These campaigns should be adapted to the unique characteristics associated with rural life.

**Conclusions**

With regards to help-seeking in rural areas, this review found little evidence for the role of perceived public stigma, limited evidence on the role of self-stigma and mixed evidence for treatment stigma. The overall methodological quality of the literature was generally low, with high levels of heterogeneity in the measures of stigma, help-seeking and rurality. A significant limitation of this review is the vast differences in definitions of rurality across different geographical contexts that make comparisons difficult. It is therefore important to interpret the results of this review in the context of the studies' methodological quality and differences in rurality. Higher quality research, with a clear theoretical understanding of the key concepts of stigma, help-seeking and rurality are required to clarify the need for targeted approaches in rural communities.

# References

Aisbett, D., Boyd, C., Francis, K., & Newnham, K. (2007). Understanding barriers to mental health service utilization for adolescents in rural Australia. *Australian Journal for Rural Health, 15*(3), 196-200. doi: 10.1111/j.1440-1584.2007.00884.x

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*(2), 179-211. https://doi.org/10.1016/0749-5978(91)90020T

Altamura, A. C., Dell'Osso, B., Berlin, H. A., Buoli, M., Bassetti, R., & Mundo, E. (2010). Duration of untreated illness and suicide in bipolar disorder: A naturalistic study. *European Archives of Psychiatry and Clinical Neuroscience*, *260*(5), 385–391. https://doi-org.ezproxy.lib.gla.ac.uk/10.1007/s00406-009-0085-2

Australian Bureau of Statistic, (2011). Australian Statistical Geography Standard (ASGS): Volume 5, Remoteness Structure.

Boyd, J. E., Katz, E. P., Link, B. G., & Phelan, J. C. (2010). The relationship of multiple aspects of stigma and personal contact with someone hospitalized for mental illness, in a nationally representative sample. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, *45*(11), 1063–1070. https://doi-org.ezproxy.lib.gla.ac.uk/10.1007/s00127-009-0147-9

Caldwell, T. M., Caldwell, T. M., Jorm, A. F., Knox, S., Braddock, D., Dear, K. B. G., & Britt, H. (2004). General Practice Encounters for Psychological Problems in Rural, Remote and Metropolitan Areas in Australia. *Australian & New Zealand Journal of Psychiatry*, *38*(10), 774–780. https://doi.org/10.1080/j.1440-1614.2004.01461.x

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://doiorg.ezproxy.lib.gla.ac.uk/10.1017/S0033291714000129

Collins, R. L., Wong, E. C., Cerully, J. L., Schultz, D., & Eberhart, N. K. (2013). Interventions to Reduce Mental Health Stigma and Discrimination: A Literature Review to Guide Evaluation of California's Mental Health Prevention and Early Intervention Initiative. *Rand Health Quarterly*, *2*(4), 3-6. doi: 10.7249/tr1318

Coppens, E., Hug, E., Wittevrongel, J., Audenhove, E., Koburger, C., Arensman, N...Ulrich, H. (2013). Public attitudes toward depression and help-seeking: Impact of the OSPI-Europe depression awareness campaign in four European regions. *Journal of Affective Disorders*. *150*(2), 320-329. http://dx.doi.org/10.1016/j.jad.2017.04.006

Cordes, S. (1990). Come on in, the water's just fine. *Academic Medicine*. *65*(12), 1–9. doi:10.1097/00001888-199012000-00025

Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist, 59*(7), 614–625. https://doi-org.ezproxy.lib.gla.ac.uk/10.1037/0003-066X.59.7.614

Corrigan, P. W., Markowitz, F. E., & Watson, A. C. (2004). Structural Levels of Mental Illness Stigma and Discrimination. *Schizophrenia Bulletin, 30*(3), 481-491. https://doi.org/10.1093/oxfordjournals.schbul.a007096

Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rüsch, N. (2012). Challenging the public stigma of mental illness: A meta-analysis of outcome studies. *Psychiatric Services, 63*(10), 963–973. https://doiorg.ezproxy.lib.gla.ac.uk/10.1176/appi.ps.201100529

Conner, K. O., Koeske, G., & Brown, C. (2009). Racial differences in attitudes toward professional mental health treatment: The mediating effect of stigma. *Journal of Gerontological Social Work, 52*(7), 695–712. https://doiorg.ezproxy.lib.gla.ac.uk/10.1080/01634370902914372

Conrad, I., Dietrich, S., Heider, D., Blume, A., Angermeyer, M. C., & Riedel-Heller, S. (2009). "Crazy? So what!": A school programme to promote mental health and reduce stigma - Results of a pilot study. *Health Education, 109*(4), 314–328. https://doi-org.ezproxy.lib.gla.ac.uk/10.1108/09654280910970893

D'Cunha, A. S. (2015). Mental illness stigma, mental health literacy, and psychological help-seeking in a rural population. (Unpublished PHD Thesis). University of North Dakota, USA.

Deen, T. L., Bridges, A. J., McGahan, T. C., & Andrews, A. R., III. (2012). Cognitive appraisals of specialty mental health services and their relation to mental health service utilization in the rural population. *The Journal of Rural Health, 28*(2), 142–151. https://doi-org.ezproxy.lib.gla.ac.uk/10.1111/j.1748-0361.2011.00375.x

Department of Health (2014). Achieving Better Access to Mental Health Services by 2020. London, UK.

Douthit, N., Kiv, S., Dwolatzky, T., & Biswas, S. (2015). Exposing some important barriers to health care access in the rural USA. *Public Health, 129*(6), 611-620. https://doi.org/10.1016/j.puhe.2015.04.001

Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open*, *6*(12), *e011458.* doi:10.1136/bmjopen-2016-011458

Fischer, E. H., & Turner, J. L. (1970). Orientations to seeking professional help: Development and research utility of an attitude scale. *Journal of Consulting and Clinical Psychology, 35,* 79-90. http://dx.doi.org/10.1037/h0029636

Green, A. C., Hunt, C., & Stain, H. J. (2012). The delay between symptom onset and seeking professional treatment for anxiety and depressive disorders in a rural Australian sample. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, *47*(9), 1475–1487. https://doiorg.ezproxy.lib.gla. ac.uk/10.1007/s00127-011-0453-x

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity.* Englewood Cliffs, N.J: Prentice-Hall.

David, H. (2004). Rural Health Disparities, Population Health, and Rural Culture. *American Journal of Public Health, 94*(10)*,* 1675-1678. doi: 10.2105/ajph.94.10.1675

Hammer, J. H., Vogel, D. L., & Heimerdinger-Edwards, S. R. (2013). Men's help seeking: Examination of differences across community size, education, and income. *Psychology of Men & Masculinity, 14*(1), 65-75. http://dx.doi.org/10.1037/ a0026813

Hart, L. G., Larson, E. H., & Lishner, D. M. (2005). Rural definitions for health policy and research. *American Journal of Public Health*, *95*(7), 1149–1155. doi:10.2105/AJPH.2004.042432

Hartley D. (2004). Rural health disparities, population health, and rural culture. *American Journal of Public Health*, *94*(10), 1675–1678. doi:10.2105/ajph.94.10.1675

Herzberg, S. E. (2013). The Influence of Incomer Status: The Role of Rural Background, Knowledge of Mental Health Services, Stigma, and Cultural Beliefs on Help-seeking Attitudes. (Unpublished PHD Thesis). University of Nebraska, USA.

Hirsch, J. K., & Cukrowicz, K. C. (2014). Suicide in Rural Areas: An Updated Review of the Literature. *Journal of Rural Mental Health, 38*(2), 65-78. http://dx.doi.org/10.1037/rmh0000018

Hoyt, D. R., Conger, R. D., Valde, J. G. & Weihs, K. (1997). Psychological Distress and Help Seeking in Rural America. *American Journal of Community Psychology, 25*(4)*,* 449-470. doi:10.1023/A:1024655521619

Jackson, H., Judd, F., Komiti. A., Fraser, C., Murray, G., Robins, G,...Wearing, A. (2007). Mental health problems in rural contexts: What are the barriers to seeking help from professional providers?. *Australian Psychologist, 42*(2), 147 - 160. DOI: 10.1080/00050060701299532

Judd, F., Jackson, H., Komiti, A., Murray, G., Fraser, C., Grieve, A., & Gomez, R. (2006). Help-Seeking by Rural Residents for Mental Health Problems: The Importance of Agrarian Values. *Australian & New Zealand Journal of Psychiatry*, *40*(9), 769–776. https://doi.org/10.1080/j.1440-1614.2006.01882.x

Komiti, A., Judd, F., & Jackson, H. (2006). The influence of stigma and attitudes on seeking help from a GP for mental health problems: A rural context. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, *41*(9), 738–745. https://doi-org.ezproxy.lib.gla.ac.uk/10.1007/s00127-006-0089-4

Kule, L. (2008). Concepts of rurality and urbanicity as analytical categories in multidimensional research. *Proceedings of the Latvian Academy of Science, 62*(1/2)*, 9-17. doi: 10.2478/v10046-008-0004-3

Link, B. G., & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology, 27*(6)*, 363-385. https://doi.org/10.1146/annurev.soc.27.1.363

Link, B. G., Mirotznik, J., & Cullen, F. T. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior*, *32*(3), 302–320. https://doi-org.ezproxy.lib.gla.ac.uk/10.2307/2136810

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine, 71*(12), 2150–2161 https://doi.org/10.1016/j.socscimed.2010.09.030

Mannarini, S., & Rossi, A. (2019). Assessing mental illness stigma: A complex issue. *Frontiers in Psychology*, *9*, 27 - 22. https://doiorg.ezproxy.lib.gla.ac.uk/10.3389/fpsyg.2018.02722

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of Internal Medicine*, *151*(4), 264 - 269, https://doi.org/10.1371/journal.pmed.1000097

Murray, G., Judd, F., Jackson, H., Fraser, C., Komiti, A., Hodgins, G., et al. (2005). The five factor model and accessibility/remoteness: Novel evidence for person – environment interaction. *Personality and Individual Differences, 39*(4), 715 – 725. https://doi.org/10.1016/j.paid.2005.02.007

Parr, H., Philo, C., & Burns, N. (2004). Social geographies of rural mental health: experiencing inclusions and exclusions. *Transactions of the Institute of British Geographers*, *29*(4), 401-419. https://doi.org/10.1111/j.0020-2754.2004.00138.

Schnyder, N., Panczak, R., Groth, N., & Schultze-Lutter, F. (2017). Association between mental health-related stigma and active help-seeking: Systematic review and meta-analysis. *The British Journal of Psychiatry*, *210*(4), 261–268. https://doi-org.ezproxy.lib.gla.ac.uk/10.1192/bjp.bp.116.189464

Smith, L. D., Peck, P. L., & McGovern, R. J. (2004). Factors Contributing to the Utilization of Mental Health Services in a Rural Setting. *Psychological Reports*, *95*(2), 435–442. https://doi.org/10.2466/pr0.95.2.435-442

Stamm, B., Metrick, S., Kenkel, M. Davenport, J., Davenport, J., Hudnall, A.,...Markstrom, C. (2001). *Introduction. In B.H. Stamm (Ed.), Rural Behavioral Health Care: An Interdisciplinary Guide (pp. 3-9).* Washington, D.C: American Psychological Association.

Stewart, H., Jameson, J. P., & Curtin, L. (2015). The relationship between stigma and self-reported willingness to use mental health services among rural and urban older adults. *Psychological Services, 12*(2), 141-148. http://dx.doi.org/10.1037/a0038651

Ritsher, B. J., & Phelan, J. C. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research, 129*(3), 257 -265. https://doi.org/10.1016/j.psychres.2004.08.003

Rost, K., Smith, G. R., & Taylor, L. (1993). Rural-Urban Differences in Stigma and the Use of Care for Depressive Disorders. *The Journal of Rural Health, 9*(1), 57-62. https://doi.org/10.1111/j.1748-0361.1993.tb00495.x

Vogel, D. L., Wade, N. G., & Haake, S. (2006). Measuring the self-stigma associated with seeking psychological help. *Journal of Counseling Psychology*, *53*(3), 325–337. https://doi-org.ezproxy.lib.gla.ac.uk/10.1037/0022-0167.53.3.325

Vogel, D. L., Wade, N. G., & Hackler, A. H. (2007). Perceived public stigma and the willingness to seek counseling: The mediating roles of self-stigma and attitudes toward counseling. *Journal of Counseling Psychology*, *54*(1), 40–50. https://doi-org.ezproxy.lib.gla.ac.uk/10.1037/0022-0167.54.1.40

Wang, P. S., Angermeyer, M., Borges, G., Bruffaerts, R., Tat Chiu, W., DE Girolamo, G., … Ustün, T. B. (2007). Delay and failure in treatment seeking after first onset of mental disorders in the World Health Organization's World Mental Health Survey Initiative. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)*, *6*(3), 177–185. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2174579/

Wood, L., Burke, E., Byrne, R., Pyle, M., Chapman, N., & Morrison, A. (2015). Stigma in psychosis: A thematic synthesis of current qualitative evidence. *Psychosis: Psychological, Social and Integrative Approaches*, *7*(2), 152–165. https://doi-org.ezproxy.lib.gla.ac.uk/10.1080/17522439.2014.926561

Wrigley, S., Jackson, H., Judd, F., & Komiti, A. (2005). Role of Stigma and Attitudes Toward Help-Seeking from a General Practitioner for Mental Health Problems in a Rural Town. *Australian & New Zealand Journal of Psychiatry*, *39*(6), 514–521. https://doi.org/10.1080/j.1440-1614.2005.01612.x

Yu, Y., Liu, Z., Hu, M., Liu, H., Yang, J. P., Zhou, L., & Xiao, S. (2015). Mental health help-seeking intentions and preferences of rural Chinese adults. *PLoS ONE*, *10*(11), e0141889. DOI: 10.1371/journal.pone.0141889

# Appendix 1

## Appendix 1.1: Author guidelines for Journal of Rural Health

*Author Guidelines*

The mission of The Journal of Rural Health is to serve as a medium for communication among health scientists and professionals in practice, educational, research, and policy settings. It is a peer-reviewed international journal devoted to advancing research related to rural health, but its focus is especially on the United States. The journal publishes Original Articles, Letters to the Editor, Commentaries, Book Reviews, and Editorials. Most Original Research articles published in the journal are full research manuscripts, but brief research reports and reviews of the scientific literature are also published.

The journal will only publish manuscripts that reflect the highest standards of practice and scientific inquiry and that report results in a style and format relevant to rural health scientists and professionals. Responsibility for the content of articles belongs to the authors.

The submission of a manuscript for review represents a certification on the part of the author(s) that it is an original work and that the manuscript, or a version of it, has not been published and is not being considered for publication elsewhere. If study findings have been previously disseminated in a working paper, policy brief, or other written (including electronic) format, the manuscript submitted to the journal should be meaningfully different. Formal, published reports that have been previously posted on the Internet in their entirety, have been intended to reach a wide audience, and are publicized and available to any interested party (whether free or not) usually will not be considered for journal publication absent substantially new data, analysis, and/or interpretation. At the time of submission, authors must disclose in a cover letter to the Editor details of related papers they have authored. View our full prior dissemination policy here.

**Reporting Guidelines:** We request that authors apply the STROBE guidelines for observational studies (cross-sectional or cohort studies pertain to the STROBE), CONSORT guidelines for randomized trials, and PRISMA guidelines for systematic reviews. Links to these and other guidelines, including for qualitative research, can be found at http://www.equator-network.org.

**Authorship Criteria:** We follow the ICMJE recommendation that each author listed must meet 3 conditions: (1) make substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) draft the article or revise it critically for important intellectual content; and (3) give final approval of the version to be published. All contributors who do not each meet all 3 criteria should be listed in the acknowledgements. Visit www.icmje.org.

**Conflicts of Interest:** Conflicts of Interest (or their absence) may be personal, commercial, political, governmental, academic, or financial. The role(s) or lack thereof of any funding organization and/or sponsor in the design and conduct of the study; in the collection, analysis, and interpretation of the data; and in the preparation, editing, or censuring of the manuscript must be specified in writing in the Disclosures section of the blinded title page submitted with the manuscript. View our full conflicts of interest policy <u>here</u>.

**Where to Submit Manuscripts: All manuscripts must be submitted in electronic form via the web-based peer review system located at** https://mc.manuscriptcentral.com/jrh. Authors who have never submitted to the journal using the online system will need to create a user account. Existing users can log in with their previously issued user ID and password. Additional instructions may be found at the website. The documents described below should be uploaded with each submission.

**Cover Letter:** A letter addressed to the Editor (Tyrone F. Borders, PhD, Editor, The Journal of Rural Health) should be uploaded as "Cover Letter" at the time of submission. This letter from the corresponding author(s) should testify that (a) the material has not been published in whole or in part elsewhere; (b) the paper is not currently being considered for publication elsewhere; (c) all authors have been personally and actively involved in substantive work leading to the report and will hold themselves jointly and individually responsible for its content; and (d) all relevant ethical safeguards have been met in relation to patient or subject protection.

**Abstract:** Submit Abstracts in a structured format (suggested subheadings are Purpose, Methods, Findings, and Conclusions) and include no more than 250 words. In the online system, you will be directed to paste your abstract into a specified field. You will also be directed to type or select 3 to 5 key words for the manuscript. Authors must also include the Abstract, followed by key words, on the first page of the main manuscript.

**Title Page: The title page should be uploaded as a separate document in the online system and must not be included in the main body of the manuscript.** Include each author's highest degree after his or her name, followed by a superscript number, and add below a corresponding affiliation note that lists the author's Department (or Unit), Institution, City, and State. The same superscript number should be repeated for authors with identical affiliations. Authors with more than one primary affiliation should list each separately. Identify the corresponding author and provide full contact information, including mailing address, e-mail, and telephone number. **Funding sources, Disclosures, Acknowledgments, and a maximum of 5 Key Words should also be included on the title page.**

**Main Manuscript:** Author identifying information may only appear on the title page and cannot appear anywhere in the main body of the manuscript; if all author identifiers are not removed from the main manuscript, the submission cannot be processed and will be returned to the submitting author. The manuscript should be submitted as a double-spaced Microsoft Word document; the paper will automatically be converted to PDF in the manuscript central system. Pages should be numbered, starting with the first page of the abstract. Please use US English spellings. If explanatory notes are necessary, use endnotes (at the end of the manuscript) rather than footnotes (at the bottom of pages). **For all citations and references, use AMA style.**

**Types of Submissions**

**Original Articles and Brief Reports:** A report of research addressing a specific research question, including the methods used, the results of the research, and conclusions drawn from the research. The body of a manuscript (abstract through conclusion) should be no more than 4,500 words (approximately 18 double-spaced pages). Manuscripts of more than 4,500 words should not be submitted without first consulting the Editorial Office. **Brief Reports** of no more than 2,000 words not including the abstract and with no more than 3 tables/figures may be submitted. The references and any tables or figures are not counted toward the word limit.

**Literature Reviews:** An assessment of existing research that is relevant to current issues in rural health. It should address a specific research question, analyze the research methods

used and the results of existing research, and discuss why further study is important. Word limits are the same as those for original research articles.

**Commentaries:** Commentaries generally discuss an issue that is relevant to the journal's scope, such as the pro and con views on an important, controversial health services or policy issue or the impact of a new policy on organizations and services. The commentary should not duplicate material being published or submitted elsewhere. Commentaries are limited to 1500 words (text and any notes) and have no abstract. The Editor makes a decision on whether to publish a submitted commentary but may request further evaluation by peer review.

**Letters to the Editor:** A letter to the editor in response to a specific article provides a means of communication between authors and readers of the JRH, allowing continued dialog about journal content to take place. Such letters should be sharply focused, not exceed 400 words, and have no abstract. Submission of a letter to the editor constitutes permission to publish the letter at the discretion of the Editor in Chief. The letter may be edited or abridged.

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**Tables should be included in the main document file but on separate pages after the reference list. Figures should be uploaded as separate EPS or PDF (600 dpi or greater) files.** All tables and figures should be numbered consecutively and referred to within the text at least once.

**For all Citations and References, use the style as outlined in the AMA Manual of Style.** Authors should always consult the primary source and never cite a reference that they themselves have not read. Each reference listed must be cited in the text, tables or figures in

consecutive numerical order using superscript Arabic numerals. Place the superscript numerals **outside periods and commas** but inside colons and semicolons. When citing two or more references at the same place in a manuscript, use hyphens to join the first and last numbers of a closed series; use commas (without spaces) to separate multiple citations (eg, The data, as previously reported,[1-3,5] had led other researchers to several different conclusions.[3,5]). When a reference is mentioned in the text, only surnames of authors are used. For a two-author reference, use both surnames; for references with more than two authors or authors and a group, include the first author's surname followed by "and associates" or "et al" if mentioned in parentheses. **Within the reference list, which should appear in the main document file following the manuscript text,** use this format for articles published in print journals: Reid-Arndt SA, Cox CR. Does rurality affect quality of life following treatment for breast cancer? *J Rural Health*. 2010;26(4):402-405. If there are more than 6 authors, list only the first 3 followed by et al. Use this style when citing a chapter in a book: Goldstein H. Multilevel Statistical Models. 2nd ed. New York, NY: Wiley; 1995. Follow this format when citing an article in an online journal: Duchin JS. Can preparedness for biological terrorism save us from pertussis? *Arch Pediatr Adolesc Med*. 2004;158(2):106-107. Available at: http://archpedi.ama-assn.org/cgi/content/full/158/2/106. Accessed June 1, 2004.

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**Appendix 1.2 Search terms**

| Database | Search terms |
|---|---|
| CINHAL & PSYCHINFO<br><br>Limits: English | S1: DE "Mental health" or DE "Mental Disorders" |
| | S2: DE "Mental Health Stigma" OR DE "Mental Illness (Attitudes Toward)" OR DE "Social Discrimination" OR DE "Prejudice" |
| | S3: TI stigma* or attitud* or prejudic* or discriminat* OR AB stigma* or attitud* or prejudic* or discriminat* |
| | S4: S2 or S3 |
| | S5: DE "Help Seeking Behaviors" OR DE "Health Care Seeking Behavior" OR DE "Health Care Utilization" OR DE "Treatment Barriers" |
| | S6: TI help-seeking or delay* or barrier* OR AB help-seeking or delay* or barrier* |
| | S7: S5 or S6 |
| | S8: S1 and S4 and S7 |
| MEDLINE & EMBASE<br><br>Limits: English | 1: mental health/ or mental disorders/ or mental disease/ |
| | 2: social stigma/ or social distance/ or social discrimination/ or prejudice/ or attitude/ |
| | 3: stigma* or attitud* or prejudic* or discriminat* .TI. .AB. |
| | 4: 2 or 3 |
| | 5: help seeking behavior/ or attitude to health/ or "patient acceptance of health care"/ or patient participation/ or treatment refusal/ |
| | 6: help-seeking or barrier* or delay* .TI. .AB. |
| | 7: 5 or 6 |
| | 8: 1 and 4 and 7 |

**Appendix 1.3: Axis quality rating tool**

| Introduction | |
|---|---|
| 1 | Were the aims/objectives of the study clear? |
| Methods | |
| 2 | Was the study design (cross-sectional) appropriate for the stated aim(s)? |
| 3 | Was the sample size justified? |
| 4 | Was the target/reference population clearly defined? (Is it clear who the research was about? Was a clear definition of rurality provided such as population density?) |
| 5 | Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation? (Did the sample align to local official guidelines or justified with research? Did the sample include non-rural samples (e.g. cities) ?) |
| 6 | Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation (e.g. random sampling) ? |
| 7 | Were measures undertaken to address and categorise non-responders? |
| 8 | Were the risk factor and outcome variables measured appropriate to the aims of the study? |
| 9 | Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously? |
| 10 | Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values) |
| 11 | Were the methods (including statistical methods) sufficiently described to enable them to be repeated? |
| Results | |
| 12 | Were the basic data adequately described? (e.g. demographics) |
| 13 | Does the response rate raise concerns about non-response bias? |
| 14 | If appropriate, was information about non-responders described? |
| 15 | Were the results internally consistent? |
| 16 | Were the results presented for all the analyses described in the methods? |
| Discussion | |
| 17 | Were the authors' discussions and conclusions justified by the results? |
| 18 | Were the limitations of the study discussed? |
| Other | |
| 19 | Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results? |
| 20 | Was ethical approval or consent of participants attained? |

**Appendix: 1.4: Overview of rural definitions**

**Deen et al. (2012):**

"This study incorporated the definition posed by Cromartie and Bucholts (2008) along with population size, adjacency to urban areas, and economic influence. Rural in this study was defined as living in a town of fewer than 5,500 people that was situated outside of the major commuting and economic patterns of the metropolitan area (in other words, living at least 30 minutes outside of major cities with populations of 30,000 or more). Participants were recruited at local 'rural' grocery stores to increase the likelihood that their economic activity was centered in the rural community. Participants provided their 5-digit ZIP /code for residence verification."

**D'Cunha (2014):**
"Although participants were allowed to select one of three options to identify their residential geographic location (Rural, Urbanised, or Metro area), for the purposes of analyses, this data was classified as either rural or urbanised. The US Census Bureau's (2010) definition of rural as areas with less than 25,000 people was used to classify towns as rural. For paper data, zip codes were used to ensure that participants had identified their geographic location as per the definition of rural used in this study. Those who identified as living within a rural area and those whose zip codes matched those of a rural area were classified as rural. When no zip codes were provided, participants' endorsements of one of the three areas were used. However, if people had identified themselves as living within a metro area, this data was put in to the urbanised category, given that there is no metro area in proximity of where data was collected or where participants could realistically have come from. The rationale for this included the fact that surveys were distributed and emailed to people who live within known urbanized areas in a larger geographic area that is predominantly rural. Some people may have classified their geographic locations as metro as this was an option, although their zip codes did not fit within the definition of metro area used in this study. The same categorisation was used for online data as well since zip codes were unintentionally not collected here."

"Since zip codes were not tracked for online surveys, it was difficult to accurately classify people's geographic locations. No definitions of rural, urbanised, and metro were provided on the demographics form, leaving it up to people to select their location, based on their own definitions of these terms. This may have limited the ability to detect differences based on location, if these were to exist."

**Green et al. (2012):**

"A stratified sample design was used based on the Australian Standardised Geographic Classification (ASGC) Remoteness classification system, which uses the Accessibility/Remoteness Index of Australia, Plus (ARIA+) to group areas according to remoteness. The sample was recruited from inner regional (IR), outer regional (OR), remote (R) and very remote (VR) areas of New South Wales."

ARIA measures remoteness in terms of access along the road network from over 11,000 localities to five categories of service centres. Areas that are more remote have less access to service centres. ARIA is a continuous and comparable index of remoteness that covers

the whole of Australia, with variable values ranging from 0 (high accessibility) to 15 (high remoteness).

Service centres were grouped into 5 categories (Table 1). For each category, GIS network analysis was used to calculate the distance travelled by road from each of the populated localities, to the edge of the nearest service centre. An ARIA+ value was then calculated for each of the populated localities.

Table 1 ARIA+ Service Centres

| Category | Population |
| --- | --- |
| A | 250,000 persons or more |
| B | 48,000 – 249,999 persons |
| C | 18,000 – 47,999 persons |
| D | 5,000 – 17,999 persons |
| E | 1,000 – 4,999 persons |

Once the distance measures had been calculated, three additional steps were necessary to produce the final ARIA+ values for each locality. The steps are described below and summarised in Figure 6.
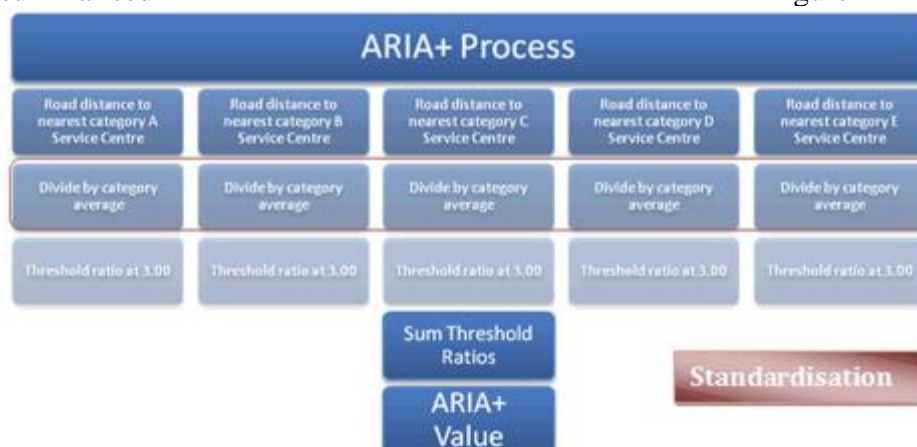


Figure 2: Diagram of the ARIA+ Value Calculation Process

The ABS remoteness structure in the 2001 and 2006 ASGC uses a five class classification scheme for ARIA at the CCD level. The five ABS remoteness classes, defined at CCD level, are termed Remoteness Areas (RAs). The numeric ARIA break points and the class descriptions used by the ABS are shown in Table 2. Figure 7 shows the spatial distribution of the 5 classes of remoteness for Australia.

Table 2 Australian Bureau of Statistics ARIA+ Remoteness Areas (RA) Classification

| ARIA+ Score | ABS Remoteness Areas |
| --- | --- |
| 0 - 0.2 | Major Cities of Australia |

| >0.2 - 2.4 | Inner Regional Australia |
|---|---|
| >2.4 - 5.92 | Outer Regional Australia |
| >5.92 - 10.53 | Remote Australia |
| >10.53 | Very Remote Australia |

Remoteness Areas:

1. Major Cities — relatively unrestricted accessibility to a wide range of goods, services and opportunities for social interaction.

2. Inner Regional — some restrictions to accessibility to some goods, services and opportunities for social interaction.

3. Outer Regional — significantly restricted accessibility to goods, services and opportunities for social interaction.

4. Remote — very restricted accessibility to goods, services and opportunities for social interaction.

5. Very Remote — very little accessibility to goods, services and opportunities for social interaction.

**Herzberg (2013):**

"In an effort to obtain a sample representative of the area, participants were recruited while visiting the local rural health primary care clinic. The center is located in Atlantic, Iowa a community of approximately 7000 people, serving rural individuals within approximately 35 mile radius from Cass and surrounding counties in Southwest Iowa."

"Modelled after Jones-Hazledine, Mclean, and Hope's (1997) study focusing on the impact of a client's knowledge of a local provider on rural help-seeking behaviors, rurality was assessed multidimensionally. The researchers initially defined rurality with six items. After performing a component analysis two separate components emerged. Component 1 defined current rural living situation and consisted of population of home town, living situation, self-definition, and population of the place lived most. These four items were used for the current study. A demographic questionnaire was utilized asking participants to respond to a 4 four-point scale identifying the population of their current hometown. The scale was created using the Census Bureau's definitions of urban and urban cluster with '1' representing a hometown with a population of 50,000 or more; '2' 2500-49,999; '3' 1000-2499; '4' less than 1000 (United States Department of Health and Human Service, 2012). Individuals were also asked to define their living situation on a scale of 1-4 with '1' representing living in town and '4' representing a "living in the country." Individuals were asked to identify the population of the place they have lived the longest with a 4 four-point scale with '1' being a residence with a population of 50,000 or greater; '2' 2500-49,999; '3' 1000-2499; '4' less than 1000 (United States Department of Health and Human Service, 2012). Participants were then asked via self-report to rate themselves on a four-point scale with "1" representing the most "rural" or (country- type person) and "4" being the most "urban" (city- type of person). The score for rurality was calculated by summing the 4 items of the rurality scale. In measuring

Rurality, higher scores indicate individuals self-identifying as being more rural. Mean: 10.30 SD: 3.05 Range: 5 – 16."

**Hoyt et al. (1997):**

"**Size of place** is operationalised into six categories that represent important distinctions in the context of the economics and demographics of the study region: farm households, rural nonfarm households, rural villages (under 2,500 population), small towns (2,500 to 9,999), small cities (10,000 to 49,999), and rural population centers (50,000 and larger). Consistent with the shifting demography of this region, over one third (36.9%) of the persons reside in rural population centers with relatively balanced distributions across the other size of place categories (farm, 10.0%; rural nonfarm, 8.5%; rural villages, 15.4%; small town, 14.9%; small city, 14.2%). We use the term rural population center because these metropolitan areas are located in a state with an economy that is predominantly agriculturally based. As such, these larger places may best be conceived as rural population centers that are in many respects distinct from larger metropolitan centers in other regions."

**Judd et al. (2006):**

"Subjects from the original study (Murray et al., 2005) who indicated their willingness to be involved in further research, who lived on farms or in small towns in adjacent geographical locations in Victoria and NSW, identified through having road side mailbox (RMB)."

"The sample for the current study was purposely selected from rural inland regions in Victoria and New South Wales. Rather than studying a heterogeneous rural sample, which may include a range of locales such as rural towns of various sizes, major regional centres, large coastal regions and peri-urban communities, these areas were selected in order to generate a sample of respondents that were representative of small rural towns and adjacent farming environs. The study focused on these locales, as it is residents in these areas that have been previously described in the literature as possessing the 'agrarian values' of interest in this study."

**Murray et al. (2005):**
The Accessibility/Remoteness Index of Australia system was used to define rurality.

**Komiti et al. (2006):**

"Participants had been randomly drawn from three categories of town size populations: a large regional centre (population size >20,000), medium sized rural towns (populations 1,000–20,000), and small rural towns (populations < 1,000)."

**Rost et al. (1993):**

"Subjects were classified as urban residents if they resided in one of two counties within the same metropolitan statistical area (MSA). Subjects were classified as rural residents if they resided in any non-MSA county surrounding the two metropolitan counties."

The United States Office of Management and Budget (OMB) defines a Metropolitan Statistical Area as one or more adjacent counties or county equivalents that have at least one

<u>urban core area</u> of at least 50,000 population, plus adjacent territory that has a high degree of social and economic integration with the core as measured by commuting ties.

**Smith et al. (2004):**

"Participants were selected from comprehensive white page listings in an eight-county rural area in a mid-western state. SeeTablebelow for an overview of the census population across the eight counties population." The US census defines rural as under 25,000.

TABLE 1
PERCENTAGES OF PARTICIPANTS IN EACH COUNTY, PARTICIPANTS
SURVEYED, AND TOTAL COUNTY POPULATION

| County | Surveys Returned* | | Mailing List | | Census Population† | |
|---|---|---|---|---|---|---|
| | *n* | % | *n* | % | *n* | % |
| 1 | 135 | 31.0 | 515 | 34.3 | 24,977 | 31.0 |
| 2 | 27 | 6.2 | 91 | 6.1 | 4,361 | 5.4 |
| 3 | 87 | 20.0 | 251 | 16.7 | 13,754 | 17.1 |
| 4 | 79 | 18.2 | 281 | 18.7 | 15,762 | 19.6 |
| 5 | 22 | 5.1 | 86 | 5.7 | 5,223 | 6.5 |
| 6 | 23 | 5.3 | 73 | 4.9 | 4,170 | 5.2 |
| 7 | 28 | 6.4 | 81 | 5.4 | 4,983 | 6.2 |
| 8 | 34 | 7.8 | 122 | 8.1 | 7,219 | 9.0 |
| Total | 435 | 100.0 | 1,500 | 100.0 | 80,449 | 100.0 |

*Surveys returned with county information intact. †Actual population based on estimated 2000 Census data retrieved at http://mcdc2.missouri.edu/websas/dp3_2kmenus/us/counties/MO29.html.

**Wrigley et al. (2005):**

"Participants were recruited from Echuca, a rural community in Victoria, Australia. Echuca is 220km north of Melbourne and has an approximate population of 10,000."

Echuca has an ARIA rating of 1.34 (Inner Regional).

**Yu et al. (2015):**

"The survey was conducted from November 2010 to August 2011 with 2052 permanent residents aged 18–60 living in the rural areas of Liuyang county, Hunan province. In order to get a sample that is as representative of all rural residents of Liuyang city as possible, a multistage cluster-sampling method was adopted to identify subjects. Two towns (Gaoping and Yong'an) were randomly selected from 33 towns of Liuyang county, and then two villages (Shiwan and Ma'an from Gaoping; Lutang and Shuishan from Yong'an) were randomly selected from each town, leading to a total sampling frame of 4 villages that were representative of rural populations in Liuyang, in terms of geography, socio-demographics, mental health care access and outreach activities."

The researcher has tried to obtain specific details regarding these villages through the author and Chinese census but was not able to identify population numbers.

**Appendix 1.5: Methodological quality ratings**

| | Rating item: Yes (Y), No (N), or unclear (U) | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 |
| Deen et al (2012) | Y | Y | N | Y | Y | N | N | N | N | Y | Y | Y | Y | N | Y | Y | Y | Y | N | Y |
| D'Cunha (2014) | Y | Y | N | N | N | N | N | Y | Y | Y | Y | Y | U | N | Y | Y | Y | Y | N | Y |
| Green et al (2012) | Y | Y | N | Y | N | Y | N | N | N | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | Y |
| Herzberg et al (2013) | Y | Y | Y | Y | Y | N | N | Y | Y | Y | Y | Y | N | N | Y | Y | Y | Y | N | Y |
| Hoyt et al (1997) | Y | Y | N | Y | N | Y | N | N | N | Y | N | N | N | N | U | N | Y | Y | N | Y |
| Judd et al (2006) | Y | Y | N | N | U | Y | Y | N | N | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | Y |
| Komiti et al (2006) | Y | Y | N | Y | N | Y | Y | N | N | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | Y |
| Rost et al (1993) | N | Y | N | N | U | N | N | N | N | Y | N | Y | U | N | Y | Y | Y | Y | N | N |
| Smith et al (2004) | Y | Y | N | Y | U | U | N | N | N | N | Y | Y | Y | N | Y | Y | Y | Y | N | Y |
| Wrigley et al (2005) | Y | Y | N | Y | U | N | N | N | N | Y | Y | N | Y | N | Y | Y | Y | Y | N | N |
| Yu et al (2015) | Y | Y | N | N | U | Y | N | N | N | Y | Y | Y | U | N | Y | Y | Y | Y | N | Y |

Chapter Two: Major Research Project

**Service user experiences of accessing support for psychosis in rural Highlands and the potential role of Smartphone technology: a qualitative exploration**


Submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (DClinPsy)


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**Plain English summary**

**Service user experience of accessing support for psychosis in rural Highlands and the potential use of Smartphone technology: a qualitative exploration**

**Background**

Psychosis is a diagnosis marked with distressing symptoms including hallucinations, delusions and apathy. Individuals living in rural areas face a number of additional barriers in accessing support that may lead to later detection and treatment of psychosis (Kelly, 2003). Digital technology is increasingly viewed as a method to increase access to support for individuals, particularly rural populations (Department of Health, 2014). The EMPOWER Smartphone application (app) was developed to support individuals with psychosis to monitor and self-manage psychosis and wellbeing with the support of peer workers and clinicians. There is growing evidence for the acceptability of Smartphone apps in the assessment of psychosis, with daily use of apps at 85% (Palmier-Claus et al., 2012).

**Aims**

The study aimed to gain an understanding of rural individuals' experiences of psychosis, with a particular emphasis on accessing various types of support. Additionally, initial perspectives and opinions on the Empower Smartphone app, as a potential tool in their recovery, were explored.

**Method**

Six individuals with a diagnosis of psychosis from a rural region (defined as a population under 3,000) in the Highlands were interviewed. During the interviews, participants were shown a presentation and given a demonstration of the Empower app. These interviews were analysed using thematic analysis to identify patterns across experiences and opinions.

**Results**

There were five main themes identified by the researcher. Three themes related to rural experiences:
- 'Rural context' - participants described limited public transport and a lack of local support services as potential barriers, and the positives of peace and quiet that rural isolation offers.

- 'Rural community' - participants described reduced privacy and increased stigma in smaller rural communities.
- 'Experiences of support' - participants described mixed experiences of continuity of care, positive experiences from third sector organisations and viewed experiences of psychosis (e.g. paranoia of services) as a potential barrier to support.

Two themes related to initial opinions on the Empower app:
- 'App increasing access' - participants viewed the app as a potentially helpful means to connect rural individuals to support, particularly with peer support workers aligned with the app. A lack of confidence in technology was described as a potential barrier to engaging with the app.
- 'Monitoring helps learning' - the monitoring of wellbeing through the app was viewed as a potential way for individuals to better understand their mental health and a tool to enhance professionals' understanding.

**Conclusion**

Rural life presents a mix of positive and negative characteristics that can influence an individual's experience of psychosis, social isolation and the support they receive. Mental health services need to consider adaptations, including further use of digital technology, when supporting this population. A Smartphone app, with integrated peer-support, was viewed as a potentially helpful source of support that may help alleviate rural barriers and isolation.

**Abstract**

**Introduction**

Individuals living in rural settings who have psychosis experience a number of challenges in accessing support due to their isolated location. These include a lack of public transportation, sparse support services, social isolation and increased stigma. Given these potential barriers, digital technology has been seen as a method to increase access to support. This study explored rural experiences of accessing support for psychosis and participants' perspectives on the potential use of a Smartphone Application (app).

**Method**

Semi-structured interviews were completed with adults with psychosis living in a rural setting (*n = 6*). During the interviews they were shown a presentation and demonstration of the Empower app. Thematic analysis was utilised to analyse participants' experiences and opinions.

**Result**

Three themes captured the participants' experiences of rural support: rural context, rural community and experiences of support. These highlighted the positive and negative experiences of rurality and accessing support, and the impact these had for the individual. A further two themes were captured from their perspectives on the app: app increasing access and monitoring helps learning.

**Conclusion**

Rural life presents a unique mix of positive and negative characteristics that can influence an individual's experience of psychosis, social isolation and the support they receive. Mental health services need to consider appropriate adaptations, including further integration of digital technology, when supporting this population. A daily monitoring app, blended with peer-support, was viewed as a potentially helpful source of support that may help alleviate rural barriers and isolation.

**Introduction**

Psychosis is a collective term used to describe conditions that affect the mind, where there has been some loss of contact with reality (Arciniegas, 2015). Psychosis is often associated with distressing experiences including changes in perception, hallucinations, delusions, apathy, and disorganised speech and behaviours. It is estimated that 1 - 2% of the population will experience psychosis during their lifetime (National Institute for Health and Care Excellence, 2014). Psychosis is associated with considerable negative effects on an individual's personal, social and occupational life (Wiersma et al., 2000). In addition to the personal cost of psychosis, there is a significant financial cost for society and services associated with this condition, with estimates suggesting a yearly cost of £13.8 billion for the United Kingdom (Kirkbride et al., 2012).

A common issue associated with psychosis is high incidence of relapse. Approximately three quarters of individuals diagnosed with schizophrenia will experience a relapse after achieving remission of symptoms (Brown et al., 2010). Unstable psychosis and higher rates of relapse are associated with increased costs for services (Ascher-Svanum et al., 2010) and a negative impact on an individual's symptoms and functioning (Raudino et al., 2014). A number of factors have been identified that may increase the likelihood of relapse in psychosis, such as poor social integration (Drake et al., 2000) and unplanned disengagement from treatment (Robinson et al., 1999). Early warning signs of relapse, such as anxiety and insomnia, have been shown to be a valid predictor of relapse (Eisner, Drake & Barrowclough, 2013). A systematic review of interventions that monitored early warning signs showed they had a positive effect on relapse rates and hospital admissions; however, the overall quality of the research reviewed was low (Morriss et al., 2013).

There has been a shift in policy towards utilising digital technology as a method to improve recovery, cost effectiveness, access and reduce waiting times (Department of Health, 2014). Research has identified digital technology as a potentially effective form of intervention for psychosis that can improve positive symptoms, hospital admissions, socialisation, social-connectedness, depression, and medication adherence (Álvarez-Jiménez et al., 2012). Smartphone use is becoming an integral part of modern life, with ownership as high as 78% in adults (Ofcom, 2018). Smartphone use among individuals with psychosis is growing with rates of ownership estimated at 66.4%, increasing to 81.4% in more recent studies (Firth et al., 2016). Smartphones offer opportunities for Ecological Momentary Assessment (EMA)

to collect data in real-time, at numerous points, within the context of the individual's day-to-day life (Shiffman et al., 2008). This enhances the assessment of psychological processes over time and temporally close events and triggers. There is growing evidence in the feasibility and acceptability of Smartphone apps in the assessment of psychosis symptoms, with adherence to daily monitoring over 85% (Palmier-Claus et al., 2012; Ainsworth et al., 2013; Ben-Zeev et al., 2014). More recently, Eisner and colleagues (2019) demonstrated that weekly app-based monitoring was feasible, valid and acceptable over a longer period of six months. A recent systematic review identified a number of factors that improve engagement and usability of mental health monitoring apps, including the use of less intensive assessment (e.g. once daily rather than multiple times), use of automatic reminders/notifications and incorporation of staff support with monitoring (Dubad et al., 2017). Due to the mobility of Smartphones and other forms of digital technology, interventions delivered in this format have been identified as a specific strategy that can aid the support of individuals with mental health difficulties in rural and remote regions (Farrell & McKinnon, 2003).

The 'Early signs Monitoring to Prevent relapse in psychosis and prOmote Wellbeing, Engagement and Recovery' (EMPOWER, ISRCTN: 99559262) app used in this study enables users to monitor experiences associated with psychosis and wellbeing by completing a daily questionnaire. The questionnaire contains 22-items reflecting 13-domains (e.g. mood, anxiety, coping, etc) with further supplementary questions to enable a more fine-grained assessment of a domain, if needed. The daily monitoring information is displayed in a weekly or monthly chart that can be shared with other individuals. The first month of use, an algorithm creates a baseline that subsequent data are compared against. If there is a small change, a targeted 'empower message' is sent to the user based on the area of change. Messages are intended to help people have a greater sense of control over their mental health and wellbeing and to support self-management. If there is a large change in wellbeing, that is suggestive of early warning signs of relapse, an Empower algorithm sends a targeted 'empower message' and triggers a Check In Prompt (ChIP). The consequences of the ChIP are that the research team, which includes mental health clinicians, complete a triage assessment. Depending on the outcome of this assessment, they can share an update with the participant's care co-ordinator. A Peer Support Worker is involved in setting up and personalising the daily questionnaire, alongside a regular fortnightly follow-up. Following this, they enable conversations to help individuals notice the *'ebb and flow'* of changes in

daily life, utilise personal and collective experiences, and encourage explorations of self-management methods. The app is currently part of a large scale cluster randomised control trial comparing the Empower app with treatment as usual in various community mental health teams across the United Kingdom and Australia.

Individuals experiencing mental health difficulties in rural areas face a particular set of difficulties due to their remote location that may exacerbate mental health issues. This includes a lack of public transportation, social isolation and increased stigma (Parr, Philo & Burns, 2004). The isolation of rural communities can be a barrier to services and may result in a delayed detection of psychosis and subsequent engagement with mental health support (Kelly, 2003). Consequently, individuals may have more severe symptoms by the time they access support. Research from rural service providers identified increased barriers with rurality, including confidentiality limitations, overlapping professional roles and training and resource issues (Brems et al, 2006). As there are additional difficulties associated with the rural aspects of living, it is important that tailored healthcare approaches are adopted. The most recent Scottish Mental Health Strategy (2017) outlined the importance of addressing issues associated with rural living to reduce isolation and improve access to health care to maintain good physical and mental wellbeing (The Scottish Government, 2017).

There is a lack of qualitative research on the perspectives of individuals experiencing psychosis in rural areas of Scotland. A qualitative exploration will provide invaluable insights on individuals' experiences of accessing support and their perception on the potential use of the Empower app. This could inform the possible integration of Smartphone technology into the care packages of individuals living with psychosis in rural areas.

**Research Aims**

The study aimed to gain a deeper understanding of the perspectives of service users in rural Highlands who have experienced psychosis. Specific details on accessing professional and informal support were explored. Additionally, initial perspectives and opinions on the Empower Smartphone app, as a potential tool in their recovery, were examined. This included exploring initial perspectives about the potential role and impact of the app on experiences of rural life and support.

**Method**

**Design**

This was a qualitative study using semi-structured interviews that were analysed using thematic analysis. Thematic analysis has no inherent theoretical underpinning and therefore has the flexibility to analyse various types of interview data (Braun & Clark, 2006). Critical realism was chosen as the epistemological approach for the analysis. Critical realism is an integration of realist ontology (there is a real world that exists independently of our perceptions and social systems) with an interpretivist epistemology (our understanding of this world is inevitably a construction from our own perspective and experiences) (Olson, 2007).

Interviews lasted between 50 and 74 minutes. A flexible topic guide was developed through consultation with the researcher's supervisor and current literature on the area (see Appendix 2.2). The first part of the interview consisted of questions relating to experiences of accessing various types of support in the Highlands. Following this, a 10 minute presentation (see Appendix 2.3) and demonstration of the Empower app was given with follow-up questions to explore their initial opinions. The researcher used the app for a month prior to interviews to become familiar with its functions.

**Ethical considerations**

This study was reviewed and approved by the West of Scotland Research Ethics Committee (18/WS/0196) and sponsored by NHS Highland Research and Development Department (1453) (Appendix 2.4). Written informed consent was obtained from each participant before interviews (Appendix 2.5) and all data were stored and handled in line with NHS data protection policies. All participant identifiable information was removed and pseudonyms have been used to ensure anonymity.

**Recruitment**

The study aimed to recruit participants living in a rural location within the Highlands. This was defined as a population of 3,000 or less (Scottish Government Urban-Rural Classification, 2016). They were required to fulfil the ICD-10 (World Health Organisation, 1992) diagnostic criteria for schizophrenia, schizotypal or delusional disorders (F20-29). Individuals who were under the age of sixteen, lived in an urban area, had a learning

disability, were in an acute psychotic episode or lacked capacity to give informed consent were not eligible to participate.

The researcher presented the study to all Adult Community Mental Health Teams and the Rehabilitation Team within NHS Highland, and to the Highland User Group (HUG - Action for Mental Health). Staff members considered their caseload for eligible individuals. Once an individual was identified, the staff member contacted them and provided them with an information leaflet (see Appendix 2.6). If verbal consent to access the individual's personal details to make contact was obtained, the researcher contacted the participant via telephone. The participant information sheet (see Appendix 2.7) was sent to the individual via email or post and they were given a minimum of 24 hours to consider this. Following this, if interested, an interview was arranged and a written consent form was completed beforehand.

The aim was to recruit a relatively small sample of homogenous participants, relevant to the area of investigation, in-line with recommendations for qualitative studies (Patton, 2002). The final sample consisted of 6 participants. A further two individuals were identified via recruitment but did not respond to correspondence inviting them to participate.

**Sample Characteristics**

The sample included two males and four females, all of whom were white and Caucasian. Participants were recruited from five different settlements within the Highlands that were classified as 'rural' and 'remote' (population under 3000, with a drive of over 30 minutes to a settlement of 10000 or more). Four participants had a diagnosis of schizophrenia and two had a diagnosis of schizoaffective disorder. All participants were under the care of a Psychiatrist and five were allocated a Community Psychiatric Nurse (CPN). The age of participants ranged from 34 to 58, with a median of 45. All participants owned a mobile phone but only three had a Smartphone. Further details on participants' characteristics can be found in Table 1.

Table 1. Overview of sample characteristics

| Name* | Gender | Age-banding | Smartphone ownership | Rural index** |
|---|---|---|---|---|
| Claire | F | 35 – 44 | Yes | Remote/Rural |
| James | M | 45 - 54 | Yes | Remote/Rural |
| Jane | F | 25 - 34 | Yes | Remote/Rural |
| Michelle | F | 45 - 54 | No | Remote/Rural |
| Sarah | F | 45 - 54 | No | Remote/Rural |
| Roy | M | 55 - 64 | No | Remote/Rural |
| *Pseudonyms **Remote/Rural: population under 3000, with a drive of over 30 minutes to a settlement of 10000 or more | | | | |

## Data Analysis

The process for thematic analysis outlined in Clarke and Braun (2006) was used. The interview recordings were transcribed verbatim by the principal researcher. The transcripts were read a number of times to enable the researcher to familiarise themselves with the data. Subsequently, transcripts were systematically reviewed and initial codes were applied (excerpt can be found in Appendix 2.8). Codes were generated when a feature of the data was identified as potentially of interest to the research. Patterns and themes were then identified in the initial coding that captured something important, meaningful or relevant to the research aims. Themes were developed based on the frequency across participants and saliency of the codes. The themes were reviewed to ensure they were coherent, distinct and supported by the data. The final stage of refining the themes involved identifying the essence of the themes and defining them. The principal researcher's supervisor supported the above process to help enhance the validity and plausibility of theme development. This involved the supervisor independently reviewing two transcripts and associated codes and themes, and possible interpretations were discussed to ensure they were grounded in the data. The principal researcher's reflections during the analysis were discussed frequently within supervision to reduce the impact of potential biases.

The notion of 'data saturation' is a frequently used principle in qualitative research to identify the point in which it is deemed that further data collection and/or analysis is not necessary as it would not offer new insights. How 'data saturation' is operationalised and measured is contentious and poorly defined within qualitative research (Saunders et al., 2018). It has been questioned whether true 'data saturation' is necessary, achievable or practically feasible (Dey, 1999). Given these concerns, this study adopted the principle of

'data sufficiency', as recruitment and analysis continued until there was a rich and detailed body of data. The point of sufficiency was defined as when there was enough detail to establish patterns and themes across participants, whilst being able to identify subtle differences within these patterns and themes. This allowed for a detailed exploration and analysis of experiences and opinions in order to answer the research objectives.

## Researcher Reflexivity

Braun and Clark acknowledge that during analysis, the researcher will have their own preconceived ideas about the data and analysis process. The themes do not simply 'emerge' but form part of an active process between the researcher and the data. This approach is in line with critical realism, as it accepts that there is a 'true' reality which can only be viewed through a subjective lens of perceptions and experience (Olson, 2007). The researcher acknowledged that working within mental health services in rural Highlands will have shaped their position during the study and interpretations of the data. Through supporting rural individuals, the researcher had seen firsthand the barriers and difficulties experienced in accessing timely and appropriate support. As this is particularly relevant to the current study and one of the reasons for the researcher engaging with this topic, this is likely to have influenced the research and analysis process. Throughout the study the researcher was aware of these potential biases and completed a reflective diary (see excerpt in Appendix 2.9). Research supervision was utilised to ensure validity of coding and themes. Due to limited time and resources, it was not possible to get participants' opinions and reflections on the themes that were developed. This would have been a useful and collaborative way to further check the validity of analysis and to ensure the themes generated aligned with their experiences.

# Results

The thematic analysis resulted in five themes, with thirteen sub-themes (see Table 1). To enable transparency within the analysis, excerpts from the transcripts have been included in the overview of the themes.

**Table 2. Themes and sub-themes**

| Theme | Sub-theme | Frequency across participants | Participants* |
|---|---|---|---|
| **Rural Context** | A lack of local services | 3 | Jane, James & Michelle |
| | Limited public transport | 3 | Claire, James & Michelle |
| | Peace and quiet | 3 | Claire, James & Michelle |
| **Rural Community** | Reduced privacy | 4 | Sarah, Jane, Claire & Michelle |
| | Mental health stigma | 3 | Sarah, Claire & Michelle |
| **Experiences of Support** | (Dis)continuities of care | 5 | Roy, Sarah, Claire, James & Michelle |
| | Experiences of psychosis a barrier to support | 4 | Roy, Sarah, Claire & Michelle |
| | Third sector support | 5 | Roy, Jane, Claire, James & Michelle |
| **App Increasing Access** | Connecting rural people to support | 5 | Roy, Jane, Claire, James & Michelle |
| | Technology confidence | 4 | Roy, Sarah, Jane & James |
| | Benefits of peer-support | 5 | Roy, Jane, Claire, James & Michelle |
| **Monitoring Helps Learning** | Learning about my mental health | 5 | Roy, Jane, Claire, James & Michelle |
| | Professionals learning about me | 5 | Roy, Jane, Claire, James & Michelle |
| *Pseudonyms | | | |

## Rural Context

This theme highlighted the positive and negative experiences associated with living in a rural area. Three sub-themes were identified within this theme: 1) a lack of local services; 2) limited public transport; and 3) peace and quiet.

### 1) A lack of local services

Some participants described a lack of local services in their community and expressed that the services that were in place were *"spread thinly"*. One participant was aware of a *"six month waiting list"* for a local counselling service and expressed that *"there isn't anything else on {island} so erm it would be nice to see that service backed up a bit."* (Michelle, 7, 285). Participants reflected that they knew of mental health services but these were centralised to more populated areas. Jane highlighted this issue through an encounter she had with her CPN: *"My nurse would bring me details of groups in {city}... but I have never been... cause I think it's quite far to go all the way there just for an hour and then to come back"* (Jane, 9, 193). With the lack of local services and the extensive travel to centralised services, participants found it *"hard to get the energy"* (James, 7, 283) to attend. These experiences suggested that the lack of local services was a barrier for some participants accessing support.

### 2) Limited public transport

A number of participants described negative experiences of public transport in their local area, with it being described as *"not so great"* and a *"shambles"*. James discussed the infrequency of the bus service to a local city: *"I have a six o'clock in the morning, a nine o'clock and that's it... So it is quite limiting."* (James, 10, 276). These issues meant that participants relied on cars and family for transport. Claire expressed that she was *"lucky I can get a lift with {partner} or my mum and dad"* (Claire, 13, 366-368). A number of participants emphasised how fortunate and *"lucky"* they felt to have alternatives to public transport and reflected that without them they would struggle to travel to amenities and access services.

**3) Peace and quiet**

Three participants described the positive effect of living in an isolated area. Participants described the helpful qualities associated with the isolation: *"the less people; the less busyness; the less stress."* (Claire, 4, 401). These qualities were highly valued and participants reflected that they *"find it relaxing"* and *"find the illness much easier to manage"* (Claire, 4, 411). Participants made comparisons of living in a city and the increased stress associated with *"too many people".* When we explored James's experiences of previously living in a town and the associated stress, he stated that he *"would never go back."* (James, 14, 411). This emphasised how strongly he felt about the negative impact of living in a town. Michelle described trips to the closest city and feeling *"glad to get home at the end of the day"* (Michelle, 14, 411). Overall, participants expressed a preference for rural living because of the benefits association with fewer people and reduced stress.

## Rural community

Participants described experiences linked with their rural communities. Within this theme, two sub-themes were identified: 1) reduced privacy; and 2) mental health stigma.

**1) Reduced privacy**

Participants discussed experiences related to a lack of anonymity within their smaller communities. Some participants described a desire to keep aspects of their mental health private but struggled to do so because of living "*in a small village {where} you can't keep secrets.*" (Claire, 4, 140). Claire goes on to describe experiences when "*there's been an ambulance coming to our house at certain times*" (Claire, 4, 142) and due to the close-knit nature of her village, neighbours soon realised there was a *"problem".* The lack of anonymity was viewed as a negative aspect of their rural community by some because of the potentially negative reaction that people may have. One participant expressed that the reduced privacy was worsened by a culture of *"gossip"* and in which *"there'll be a different story from different people."* (Sarah, 8, 337). In contrast, one participant expressed that it was beneficial that she lived in a *"small town"* where "*lots of people know me"* (Jane, 5, 168) because of the support and sense of community this created for her.

**2) Mental health stigma**

Three participants described experiences of negative attitudes towards people with mental health difficulties in their communities. The views within their communities were described as *"traditional"*, with a variety of negative stereotypes about mental health. These negative stereotypes included *"{people} confus{ing} mental ill health with erm character flaws"* (Michelle, 5, 218) and mental health being *"self-inflicted…{because} they're all benefit cheats."* (Michelle, 5, 227). These attitudes have led participants to be reluctant to be open about their mental health within their communities; one participant stated that she *"didn't want people to know"* because she felt *"ashamed"* (Sarah, 4, 169). Claire highlighted that there were still high levels of stigma associated with schizophrenia, with "*more acceptance"* for other mental health issues such as depression. Claire was extremely fearful that other people would find out about her diagnosis *"in case they get horrified"* (Claire, 3, 126). Claire expressed that she believed that stigma was perpetuated by the media portraying stories of individuals with schizophrenia that *"hurt"* people.

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**Experiences of support**

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There were three sub-themes that were identified from this theme: 1) (dis)continuities of care; 2) experiences of psychosis a barrier to support; and 3) third-sector support.

**1) (Dis)continuities of care**

Different participants discussed either positive experiences of having a consistent professional or the negative experiences and impact of having inconsistent care. Participants really emphasised the importance of having a consistent professional and the helpfulness this had on communication and engagement with support. One participant described a CPN who she had *"been seeing…for years now"* and this allowed her to develop an effective therapeutic relationship in which she could *"tell {CPN} more than I tell anybody about what's going on in my head."* (Sarah, 2, 86). This was echoed by a number of participants who highlighted that getting to know the professional made it *"easier to open up"*. James found it hard to discuss his mental health with his CPN initially but explained that *"each time she came it was a little bit easier…Now I feel I can say anything."* (James, 3, 96).

In contrast, some participants described experiences that demonstrate how a lack of a consistent professional meant that they did not *"think it was particularly helpful"* (Sarah, 7, 276). The lack of a consistency led to concerns and sometimes resistance with professionals

implementing changes in care. This was particularly highlighted by Michelle's experience of support with locum psychiatrists:

> *"It was really hopeless... the visiting locum psychiatrist would say "aww I tell you what, I think we might change your medication"...I would go no because you're not going to be here next time to deal with the consequences of that so unless you're going to actually be my psychiatrist for quite a time I don't want you meddling."* (Michelle, 2, 43-49).

**2) Experiences of psychosis a barrier to support**

Four participants described experiences associated with their psychosis and deteriorating mental health that made it more difficult for them to access support. Participants recounted times in which they were *"not in reality"* with regards to their psychosis and this made it difficult for them to recognise deterioration of their mental health. This lack of recognition and awareness meant that they were not as likely to actively seek support and communicate with professionals. For example, Sarah stated that *"When I am feeling bad and the voices, I'm not in reality at all. I wouldn't even think of phoning {CPN}."* (Sarah, 4, 149). Similarly, a number of participants described a fear or paranoia of other people, and reflected that this has made them more *"uncomfortable with other people"* which meant that they *"probably didn't ask for as much help"* (Claire, 8, 211). Michelle explained that when her psychosis worsened, she would experience heightened paranoia linked with professional support and would interpret her GP surgery as a *"hostile environment"* where she would get *"messages"*. This led her to be concerned that she *"wouldn't have the awareness to alert anyone"* (Michelle, 3, 115) if her mental health deteriorated.

**3) Third-sector support**

The role of third-sector support in rural communities was of clear importance to the participants. There was a variety of different types of support that participant received. This included practical help, such as *"changing a light bulb or getting a lift"* (Jane, 7, 158) or social contact in which they would just *"come and meet and talk to people"* (Roy, 5, 132). For a number of participants, third-sector support was a crucial source of emotional support in which they could openly talk about their mental health. This was highlighted by James who commented that *"without him {peer support worker} I am totally lost."* (James, 1, 3). James went onto state that this support *"makes {psychosis} a hell of a lot easier to cope with if somebody can come sit and just listen."* (James, 4, 159). Despite the varying types and

levels of input, the characteristic that seemed to be valued, from the participants' perspectives, was the relationship and contact with supportive people. One participant reflected that the limited support offered by *"mainstream"* services meant that the support that they would usually offer "*may well fall onto to {third-sector} services.*" (Michelle, 4, 179).

### App increasing access

Within this theme, three sub-themes were identified: 1) connecting rural people to support; 2) technology confidence; and 3) benefits of peer-support.

### 1) Connecting rural people to support

In the context of reduced rural support previously explored, the app was seen as a potentially valuable method in "*connecting you to support... {which} can sometimes be hard when you live in {rural areas}*" (Claire, 14, 609). Living in rural locations resulted in participants feeling unheard and disconnected: "*in a rural place you're lost, a little voice tryna shout for help"* (James, 9, 392). The app was viewed as a potential means to reduce isolation and a valuable source of support. Roy reflected that "*isolation can lead to psychotic symptoms*" (Roy, 21, 543) and the app could be a potential way to prevent this "*because its err a direct communication with the outside world*". It was recognised that the remote contact with peers and professionals may be beneficial because of the lack of direct contact available in rural areas. Furthermore, the Empower messages were viewed as a potential source of positivity, self-help and "*good advice and pointers*" (Jane, 11, 374) that could encourage self-management of difficulties. Overall, various aspects of the app were viewed as a potentially helpful tool in supporting self-management and connecting individuals to peer and professional support.

### 2) Technology confidence

There were concerns expressed by participants regarding a lack of confidence in using technology and a Smartphone. This lack of confidence was viewed as a potential barrier to fully engaging with the app and accessing the support it may offer. Three of the four participants who expressed concerns did not own a Smartphone. One participant stated that she "*would be absolutely worrying myself sick about pressing the right thing*" (Sarah, 13, 575). While Sarah's levels of anxiety about technology appeared higher than other participants, it seemed that it was the lack of understanding and familiarity with technology

that were fuelling participants' concerns. One participant expressed the app may be more appealing to younger people and the older generation may be more *"apprehensive"* about trying new things because they *"can get sort of set in their way"* (Roy, 14, 356). The integration of a peer support worker to offer practical support and *"to talk me through it"* (James, 13, 363) was viewed as a potentially helpful means to enhance engagement.

**3) Benefits of peer support**

The role of peer support workers and its incorporation in the app was highly valued by participants. It seemed that peer support was seen as a complimentary component of the app that was potentially *"very important"* (Roy, 13, 511). Accessing support from people who have had similar mental health experiences was seen as particularly beneficial by participants. For example, Claire stated that *"If someone experiences similar things that you feel, it's quite good to have someone that understands things"* (Claire, 13, 570). This shared understanding was seen as helpful in the process of developing a collaborative relationship because *"it's easier to relate to them"* (Jane, 11, 386). Additionally, it seemed that participants viewed peers with shared experiences as being particularly knowledgeable and experts who could *"have a lot to bring to the table…{and} have lots of suggestions to make"* (Michelle, 13, 564).

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**Better understanding of mental health**

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Two sub-themes were identified within this theme: 1) learning about myself and 2) professionals learning about me.

**1) Learning about myself**

The app was viewed as a potential means to get a better understanding of one's mental health and relate changes in their wellbeing to external experiences. For example, one participant stated that the monitoring charts may potentially support reflection on *"what causes issues or makes you feel better with your mental health"* (Roy, 18, 471). Participants stated that the app and monitoring charts might prompt them to question or *"interrogate"* their mental health, which could help them to *"understand themselves better"* (Jane, 17, 331). The use of real time monitoring and charts to *"correlate"* changes in mental health and *"what's happening in your external life"* (Michelle, 17, 508) was seen as potentially important. Some participants had *"never tried to monitor"* (Claire, 18, 517) before and viewed this new approach as a beneficial way to *"check in"*. The *"systematic"* manner of the monitoring

could potentially offer a *"logical procedure"* (Roy, 17, 419) in times of *"illogical"* thinking associated with psychosis.

**2) Professionals learning about me**

Many participants commented that they would be keen to share the monitoring charts with professionals. There were a number of potential benefits of sharing the charts with professionals, including aiding communication and giving professionals *"more detailed information to work on"* (Claire, 12, 526). Sharing the charts may enable professionals to see the *"ups and downs"*, which participants expressed *"would help them to understand"* them better (Jane, 10, 362). It seemed that the charts were viewed as a possible way to aid joint learning and collaborative working between participants and their professionals: *"It would help her {CPN} get a picture of when I was starting to go down and then we could go back and try and find a cause…hopefully help find a way to help me from doing it again."* (James, 8, 334).

**Discussion**

This study sought to understand the experiences of people with psychosis in a rural setting and their initial anticipatory expectations on a Smartphone app. While each experience was unique, there were commonalities within their lived experience and perspectives on the app.

Participants identified limited public transport and a lack of local support as issues that prevented them from accessing services and amenities. This is in keeping with the National Rural Mental Health Survey Scotland (2017) which found that nearly 50% of rural respondents believed public transport acted as a barrier to receiving care for their mental health. It is possible that the lack of local services, coupled with limited public transport, lead to a magnified effect of rural isolation. The Empower app was viewed as a potential method to connect rural individuals to mental health support that is not available in their local area. There is a growing evidence base for the effectiveness of digital mental health programmes in rural communities. Evidence suggests that the use of online self-help programmes and applications, in rural populations, leads to a reduction in mental health symptoms and stigmatising attitudes, and an improvement in mental health literacy (Griffiths & Christensen, 2007). Whilst this is promising, the use of digital health technology in rural populations should be considered in the context of potentially low technology confidence identified in this study. A lack of confidence and familiarity in technology has been found to inhibit engagement with digital health technology (Doades & Winkelmann, 2016). The lack of confidence identified in this study may represent wider issues with digital integration in rural communities. Scottish rural communities have been identified as particularly vulnerable to digital exclusion due to a lack of a digital infrastructure (Velaga et al., 2012). With this in mind, it is important that digital health integration within rural communities is done so in a manner that adapts for this. The Empower app's practical support via peer support workers is an example of how this could be potentially achieved.

'Old-fashioned' views within the community appeared to perpetuate mental health stigma which has been shown to be higher in rural communities (Hammer et al., 2013). Stigma has been found to have a significant negative effect on active mental health help-seeking, which highlights the need for strategies to increase rural understanding and acceptance (Schnyder et al., 2017). A further potential barrier to support was a deterioration of psychosis and a subsequent reduction in abilities to recognise the need for support. This is in line with research which showed that a lower level of 'insight' was one of the strongest predictors of

poorer engagement with therapy (Álvarez-Jiménez et al., 2009). This highlights the importance of real time monitoring of experiences through the Empower app as this aims to enhance recognition of early warning signs in the hope to prevent deterioration, relapse and subsequent disengagement. Set against these potential barriers, participants also reflected on the benefits of living in rural settings, including reduced stress and fewer people. Research has found a link between the stressors of urban living and exacerbated psychosis symptoms (Heinz, Deserno & Reininghaus, 2013). A further positive experience that participants discussed was the third-sector support they received. It appears that third-sector services and voluntary services in rural Scotland play more of a 'substantial' rather than an 'additional' role (Woolvin & Rutherford, 2013).

A number of themes relating to both participants' rural experiences and their perspectives on the app highlighted the importance of relationships. This included relating to others to establish a meaningful connection and shared understanding, and to oneself to develop an increased awareness of their own mental health. The importance of feeling connected and the negative impact of loneliness on psychosis has been well established (Michalska da Rocha et al., 2018). Research suggests that a self-perpetuating cycle of exclusion may transpire, in which psychosis limits connections, which in turn increases risk of deterioration of symptoms and further disengagement (Gayer-Anderson & Morgan, 2013). When considering this cycle and the additional isolation related to rural living identified in this study, the importance of services and digital technology enhancing and fostering connections and relationships is apparent. This includes ensuring continuity of care with professionals, which was viewed as an important process in establishing a meaningful working relationship in this study and previous qualitative research (Green et al., 2008). The quality of working relationships with clinicians appears to be an important determinant of patients' attitudes towards treatment for psychosis and adherence to medication (Day et al., 2005). Alongside the importance of continuity of care, participants viewed the Empower app as a potential method to facilitate connections to support, communication with others and understanding of oneself. The incorporation of remote peer support workers, and the shared understanding and potential relationship this may bring, was highly valued. This is in line with a recent systematic review that concluded that incorporating peer-support in digital interventions for psychosis may increase compliance by creating a more engaging and acceptable online environment (Biagainti, Quraishi & Schlosser, 2018).

**Implications for clinical practice and services**

The findings have clinical relevance and may support service development that encourages engagement of rural residents with psychosis. Mental health services play a crucial role in ensuring equity of access for rural residents (Scottish Mental Health Strategy, 2017). It is important to review current rural service models to identify ways to enhance continuity of care, for example identifying methods that encourage the retention of trained staff in rural locations. Due to the centralisation of a significant amount of services, it may be beneficial to explore the wider use of video conferencing consulting services and Smartphone technology to bridge the physical gap between services and rural communities. The stigma in rural areas highlights the need for targeted initiatives and educational programmes aimed at reducing mental health stigma, which have been shown to increase mental health knowledge and reduce negative attitudes (Dalky, 2012).

The findings suggest that Smartphone technology would be an acceptable method to monitor symptoms and access support in a rural setting. The inclusion of peer support workers was particularly appealing, highlighting the complementary role of digital technology and peer support. The findings show that rural communities have specific characteristics that need to be taken into account when thinking about digital inclusion policies. This includes ensuring appropriate support and training on the use of digital health tools to enhance confidence and engagement in this method of support.

**Methodological strengths and limitations**

A strength of this study was its ability to engage a hard to reach group of individuals to gain rich and detailed qualitative data. It is acknowledged that the results may have been influenced by the heterogeneity in demographics and characteristics within the sample. This included differences such as age, Smartphone ownership and whether participants were from an island community or mainland. The impact of these different variables could potentially be explored in future research.

Thematic analysis has traditionally been criticised for a lack of any clear or overt guidelines (Nowell et al., 2017); however, Braun and Clark (2006) introduced a step-by-step process to increase levels of consistency and transparency. Initially, Interpretive Phenomenological Analysis (IPA) was considered; however, following further consideration it was deemed that thematic analysis was more appropriate. IPA explores the meaning attached to everyday

lived experience (Smith, 2009) and because a significant part of the interview focused on opinions on a novel Smartphone app, IPA was deemed not suitable. The theoretical flexibility of thematic analysis allowed for analysis of previous lived experiences and current opinion based data using a critical realist approach. Unfortunately, due to time constraints of the project, a presentation and demonstration of the app was utilised rather than the participants using the app for a period of time. This may have limited participants' level of understanding and experience of the app.

It is important to recognise that whilst qualitative research aims to recruit a small homogenous group of participants, the number of individuals recruited in this exploratory study is at the lower end of acceptable when using thematic analysis. There were a number of potential difficulties with recruitment that may have contributed to this, including significant travel commitments due to the geographically dispersed population and recruiting via staff members from rural health services with high workloads and commitments. Furthermore, only recruiting through mental health teams and the Highland User Group may have resulted in individuals not accessing support from these services being excluded from the study. On reflection, it may have been helpful to explore other methods of recruitment, such as the use of local advertisements and the use of technology during recruitment and data collection. The use of videoconferencing technology has been found to be an acceptable method of data collection in qualitative research (Lo Iacona, Symonds & Brown, 2016). The use of videoconferencing technology during interviews would likely have freed up time and resources that could have been focused on further recruitment.

**Conclusions**

Rural life presents a unique mix of characteristics that can influence, both positively and negatively, an individual's experience of psychosis and the support they receive. Rural residents experience potential barriers to support due to limited public transport, reduced local services and mental health stigma in their community. The negative impact of social isolation and the importance of feeling connected and understood by others were highlighted in a number of themes. The Empower app was viewed as a possible means to connect to support, increase self-awareness and professional understanding of participants' mental health. A lack of technological understanding and confidence in rural communities was raised as a potential barrier to engaging with the app. Overall, a Smartphone app was viewed

a potentially beneficial source of support for psychosis that may enhance the experiences of rural residents.

**Future research**

Given that the app was generally well received, it would be useful to further assess the feasibility, usability and impact on relapse within a rural population. This would hopefully identify strengths and issues that could lead to rural adaptations, if needed. It would also be beneficial to assess the experiences and perceptions on the app with individuals with psychosis in an urban setting to make direct comparisons. This would help understand if there are any meaningful differences between their experiences. It would also be beneficial to explore the attitudes and opinions of mental health professionals on the use of Smartphone technology within a rural setting. This would identify potential factors that could impede or facilitate professional engagement with Smartphone technology in rural services.

# References

Ainsworth, J., Palmier-Claus, J. E., Machin, M., Barrowclough, C., Dunn, G., Rogers, A., … Lewis, S. (2013). A comparison of two delivery modalities of a mobile phone-based assessment for serious mental illness: native smartphone application vs text-messaging only implementations. *Journal of Medical Internet Research, 15*(4), e60. DOI:10.2196/jmir.2328

Álvarez-Jiménez M., Gleeson J. F., Bendall S., Lederman R., Wadley G., Killackey E., et al. (2012). Internet-based interventions for psychosis: a sneak-peek into the future. *Psychiatry Clinics of North America, 35*(3), 735–747. DOI:10.1016/j.psc.2012.06.011.

Arciniegas D. B. (2015). Psychosis. *Behavioral Neurology and Neuropsychiatry, 21*(3), 715–736. DOI:10.1212/01.CON.0000466662.89908.e7

Ascher-Svanum, H., Zhu, B., Faries, D.E., Salkever, D., Slade, E.P., Peng, X., & Conley, R.R. (2010). The cost of relapse and the predictors of relapse in the treatment of schizophrenia. *BMC Psychiatry, 10*(2). Article ID 2. https://doi.org/10.1186/1471-244X-10-2

Ben-Zeev, D., Brenner, C.J. Begale, M., Duffecy, J., Mohr, D.C., & Mueser, K.T. (2014). Feasibility, Acceptability and preliminary efficacy of a smartphone intervention for schizophrenia. *Schizophrenia Bulletin, 40*(6), 1244-53. doi:10.1093/schbul/sbu033

Biagianti, B., Quraishi, S. H., & Schlosser, D. A. (2018). Potential benefits of incorporating peer-to-peer interactions into digital interventions for psychotic disorders: A systematic review. *Psychiatric Services*, 69(4), 377–388. https://doiorg.ezproxy.lib.gla.ac.uk/10.1176/appi.ps.201700283

Birchwood, M. (2003). Pathways to emotional dysfunction in first-episode psychosis. *British Journal of Psychiatry, 182*(5), 373–375. DOI: https://doi.org/10.1192/bjp.182.5.373

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

Brems, C., Johnson, M. E., Warner, T. D., & Roberts, L. W. (2006). Barriers to healthcare as reported by rural and urban interprofessional providers. *Journal of Interprofessional Care*, 20(2), 105-118. https://doiorg.ezproxy.lib.gla.ac.uk/10.1080/ 13561820600622208

Brown, S., Kim, M., Mitchell. C. & Inskip, H. (2010). Twenty-five year mortality of a community cohort with schizophrenia. *The British Journal of Psychiatry, 196*(2), 116–121. DOI:10.1192/bjp.bp.109.067512.

Dalky, H. F. (2012). Mental Illness Stigma Reduction Interventions: Review of Intervention Trials. *Western Journal of Nursing Research*, 34(4), 520–547. https://doi.org/ 10.1177/0193945911400638

Day, J. C., Bentall R. P., Roberts, C., Randall, F., Rogers, A., Cattell, D., … Power, C. (2005). Attitudes Toward Antipsychotic Medication: The Impact of Clinical Variables and Relationships With Health Professionals. *Arch Gen Psychiatry, 62*(7), 717–724. DOI:10.1001/archpsyc.62.7.717

Department of Health. (2014). Closing the Gap: Priorities for Essential Change in Mental Health. London, UK

Dey, I. (1999). *Grounding Grounded Theory: Guidelines for Qualitative Inquiry,* London, Academic Press.

Doades, S J., & Winkelmann, Z. K. (2016). Facilitators and Barriers to Mobile Health (mHealth) Application Adoption. *Athletic Training and Sports Health Care, 23*(3), 212-220. https://doi.org/10.3928/19425864-20181101-02

Drake, R. J., Haley, C. J., Akhtar, S., & Lewis, S. W. (2000). Causes and consequences of duration of untreated psychosis in schizophrenia. *The British Journal of Psychiatry*, *177*(6), 511–515. https://doi-org.ezproxy.lib.gla.ac.uk/10.1192/bjp.177.6.511

Dubad, M., Winsper, C., Meyer, C., Livanou, M., & Marwaha, S. (2018). A systematic review of the psychometric properties, usability and clinical impacts of mobile mood-monitoring applications in young people. *Psychological Medicine*, *48*(2), 208–228. https://doi.org/10.1017/S0033291717001659

Eisner, E., Bucci, S., Berry, N., Emsley, R., Barrowclough, C., & Drake, R. (2019). Feasibility of using a smartphone app to assess early signs, basic symptoms and psychotic symptoms over six months: A preliminary report. *Schizophrenia Research, 208*, 105-113. https://doi.org/10.1016/j.schres.2019.04.003.

Eisner, E., Drake, R., & Barrowclough, C. (2013). Assessing early signs of relapse in psychosis: Review and future directions. *Clinical Psychology Review*, *33*(5), 637–653. https://doi-org.ezproxy.lib.gla.ac.uk/10.1016/j.cpr.2013.04.001

Farrell, S. P., & McKinnon, C. (2003). Technology and rural mental health. *Archives of Psychiatric Nursing*, *17*(1), 20–26. https://doi-org.ezproxy.lib.gla.ac.uk/ 10.1053/apnu.2003.4

Firth, J., Cotter, J., Torous, J., Bucci, S., Firth, J. A., & Yung, A. R. (2016). Mobile phone ownership and endorsement of "mHealth" among people with psychosis: A meta-analysis of cross-sectional studies. *Schizophrenia Bulletin*, *42*(2), 448–455. https://doi-org.ezproxy.lib.gla.ac.uk/10.1093/schbul/sbv132

Franz, L., Carter, T., Leiner, A. S., Bergner, E., Thompson, N. J., & Compton, M. T. (2010). Stigma and treatment delay in first-episode psychosis: a grounded theory study. *Early Intervention in Psychiatry*, *4*(1), 47–56. DOI: 10.1111/j.1751-7893.2009.00155.x

Gayer-Anderson, C., & Morgan, C. (2013). Social networks, support and early psychosis: A systematic review. *Epidemiology and Psychiatric Sciences*, *22*(2), 131–146. https://doi-org.ezproxy.lib.gla.ac.uk/10.1017/S2045796012000406

General Register Office for Scotland. (2005). Occasional Paper No.11, Scotland's Census: Statistics on Migration. Available at: http://www.gro-scotland.gov.uk/statistics/theme/migration/census2001-migration-stats/.

Green, C. A., Polen, M. R., Janoff, S. L., Castleton, D. K., Wisdom, J. P., Vuckovic, N.,... Oken, S. L. (2008). Understanding how clinician-patient relationships and relational continuity of care affect recovery from serious mental illness: STARS study results. *Psychiatric Rehabilitation Journal, 32*(1), 9-22. http://dx.doi.org/10.2975/32.1.2008.9.22

Griffiths, K. M., & Christensen, H. (2007). Internet-based mental health programs: A powerful tool in the rural medical kit. *The Australian Journal of Rural Health*, *15*(2), 81–87. https://doi-org.ezproxy.lib.gla.ac.uk/10.1111/j.1440-1584.2007.00859.x

Hammer, J. H., Vogel, D. L., & Heimerdinger-Edwards, S. R. (2013). Men's help seeking: Examination of differences across community size, education, and income. *Psychology of Men & Masculinity, 14*(1), 65-75. http://dx.doi.org/10.1037/a0026813

Heinz, A., Deserno, L., & Reininghaus, U. (2013). Urbanicity, social adversity, and psychosis. *World Psychiatry*, *12*(3), 187-197. https://doi.org/10.1002/wps. 20056

Komiti, A., Judd, F., & Jackson, H. (2006). The influence of stigma and attitudes on seeking help from a GP for mental health problems: A rural context. *Social Psychiatry and Psychiatric Epidemiology, 41*(9), 738–745. http://doi.org/10.1007/s00127-006-0089-4

Kauer, S. D., Reid, S. C., Crooke, A. H. D., Khor, A., Hearps, S. J. C., Jorm, A. F., … Patton, G. (2012). Self-monitoring using mobile phones in the early stages of adolescent depression: Randomized controlled trial. *Journal of Medical Internet Research*, *14*(3), 19–35. https://doi-org.ezproxy.lib.gla.ac.uk/10.2196/jmir.1858

Kelly, M. (2003). The Identification of the Duration of Untreated Psychosis in a Sample Population of Individuals with a First Episode of Psychosis in East Dorset. *Dorset Healthcare NHS Trust*, Poole.

Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, D., Boydell, J, et al. (2012). Incidence of Schizophrenia and Other Psychoses in England, 1950–2009: A Systematic Review and Meta-Analyses. *PLoS ONE, 7*(3), e31660. DOI:10.1371/journal.pone.0031660.

Lal. S., Dell'Elce, J., Tucci, N., et al. (2015). Preferences of young adults with first-episode psychosis for receiving specialised mental health services using technology: a survey study. *Journal of Mental Health, 2*(2), e18. DOI:10.2196/mental.4400

Lo Iacona, V. L., Symonds, P., & Brown, D. (2016). Skype as a tool for qualitative research interviews. *Sociological Research Online, 21*(2), 12–13. https://doi.org/10.5153/sro.3952

Mahlke, C. I., Krämer, U. M., Becker, T., & Bocka, T. (2014). Peer support in mental health  services. *Current Opinion in Psychiatry*, 27(4), 267–281. https://doi-org.ezproxy.lib.gla.ac.uk/10.1097/YCO.0000000000000074

Michalska da Rocha, B., Rhodes, S., Vasilopoulou, E., & Hutton, P. (2018). Loneliness in psychosis: A meta-analytical review. *Schizophrenia Bulletin*, *44*(1), 114–125. https://doi-org.ezproxy.lib.gla.ac.uk/10.1093/schbul/sbx036

Morriss, R., Vinjamuri, I., Faizal, M. A., Bolton, C. A., & McCarthy, J. P. (2013). Training to recognize the early signs of recurrence in schizophrenia. *Schizophrenia Bulletin*, *39*(2), 255–256. https://doiorg.ezproxy.lib.gla.ac.uk/10.1093/schbul/sbs191

National Institute for Health and Care Excellence (2014). Psychosis and schizophrenia in adults:  Treatment and management. [Online] https://www.nice.org.uk/guidance/ cg178/evidence/full-guideline-490503565

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods, 16*(1), 80 - 92. https://doi.org/10.1177/1609406917733847

Palmier-Claus, J., Ainsworth, J., Machin, M., Barrowclough, C., Dunn, G., Barkus, E., ... Lewis, S. (2012). The feasibility and validity of ambulatory self-report of psychotic symptoms using a Smartphone software application. *BMC Psychiatry, 12*(1), Article ID 172. https://doi.org/10.1186/1471-244X-12-172

Parr, H., Philo, C. & Burns, N. (2004). Social geographies of rural mental health: experiencing inclusions and exclusions. *Transactions of the Institute of British Geographers, 29*(4), 401-510. https://doi.org/10.1111/j.0020-2754.2004.00138

Ofcom. (2018). Communications market report. Available online: https://www.ofcom.org.uk/ data/assets/pdf_file/0022/117256/CMR-2018-narrative-report.pdf

Olsen, W. (2007). Critical Realist Explorations in Methodology. *Methodological Innovations Online*, *2*(2), 1–5. https://doi.org/10.4256/mio.2007.0007

Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, California: Sage Publications.

Radanovic, M., de Sousa, R. T., Valiengo, L. L., Gattaz, W. F., & Forlenza, O. V. (2013). Formal thought disorder and language impairment in schizophrenia. *Arquivos de Neuro-Psiquiatria*, *71*(1), 55–60. https://doi-org.ezproxy.lib.gla.ac.uk/10.1590/S0004-282X2012005000015

Robinson, D., Woerner, M. G., Alvir, J. M. J., Bilder, R., Goldman, R., Geisler, S., … Lieberman, J. A. (1999). Predictors of relapse following response from a first episode of schizophrenia or schizoaffective disorder. *Archives of General Psychiatry*, *56*(3), 241–247. https://doiorg.ezproxy.lib.gla.ac.uk/ 10.1001/archpsyc.56.3.241

Raudino, A., Carr, V. J., Bush, R., Saw, S., Burgess, P., & Morgan, V.A. (2014). Patterns of service utilization in psychosis: Findings of the 2010 Australian National Survey of Psychosis. *Australian and New Zealand Journal of Psychiatry, 48*(4), 341–351. DOI: 10.1177/0004867413511996

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., … Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality and Quantity, 52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Skerrat, S., Meador, E., & Spencer, M. (2017). National Rural Mental Health Survey Scotland: Report of Key Findings. Scotland.

Schnyder, N., Panczak, R., Groth, N., & Schultze-Lutter, F. (2017). Association between mental health-related stigma and active help-seeking: Systematic review and meta-analysis. *British Journal of Psychiatry, 210*(4), 261-268. doi:10.1192/bjp.bp.116. 189464

Shiffman, S,, Stone, A. A., & Hufford, M. R. (2008). Ecological momentary assessment. *Annual Review of Clinical Psychology 4,* 1–32. https://doi.org/10.1146/annurev. clinpsy.3.022806.091415

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis. Theory, Method and Research.* London: Sage Publications.

The Scottish Government (2011). Scotland's Digital Future A Strategy for Scotland. [Online]; https://www2.gov.scot/resource/doc/981/0114237.pdf

The Scottish Government (2012). Rural Scotland Key Facts. [Online] ;http://www.scotland .gov.uk/Publications/2012/09/7993/0.

The Scottish Government (2017). Mental Health Strategy 2017-2027. [Online] ;https:// www.gov.scot/publications/mental-health-strategy-2017-2027/

Wiersma, D., Wanderling, J., Dragomirecka, E., Ganev, K., Harrison, G., an der Heiden, W., ... Walsh, D. (2000). Social disability in schizophrenia: its development and prediction over 15 years in incidence cohorts in six European centres. *Psychological Medicine*, *30*(5), 1155-1167. https://doi.org/10.1017/S0033291799002627

Woolvin, M. & Rutherford, A. (2013). *Volunteering and public service reform in rural Scotland. Research Report.* Edinburgh: SRUC Rural Policy Centre.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines.* Geneva: World Health Organization.

Velaga, N. R., Beecroft, M., Nelson, J. D., Corsar, D., & Edwards, P. (2012). Transport poverty meets the digital divide: accessibility and connectivity in rural communities. *Journal of Transport Geography, 21*(1), 102-112. https://doi.org/10.1016/j.jtrangeo.2011.12.005

**Appendix 2**

**Appendix 2.1: Author guidelines for JMIR**

## Author Guidelines

A Word-template of an article compatible with journals from JMIR Publications can be downloaded from https://asset.jmir.pub/assets/public/InstructionsForAuthorsOfJMIR.docx. Note that the references can be in any format, as long as the in-text citations are sequentially numbered in the manuscript with square brackets and as long as the reference at the end has a PMID in the format PMID:123456. See **Instructions for Authors for details.** .

As a service for our authors we offer the possibility to have a submission considered in other journals, e.g. manuscript and peer-review reports may be **transferred** to a JMIR sister/partner journal, if the paper is not found suitable for publication in JMIR, but is publishable in another journal. These journals include e.g. i-JMR, JMIR Res Protoc, JMIR mHealth and uHealth, JMIR Medical Informatics, JMIR Human Factors, JMIR Mental Health, JMIR Public Health, JMIR Cancer and others. The submission fee for that partner journal (if any) will be waived, and transfer of the peer-review reports may mean that the paper does not have to be re-reviewed. Authors will receive a notification when the manuscript is transferred, and at that time can decide if they want to pursue publication in a sister/partner journal. **If authors do NOT wish an automatic transfer to an alternative journal after rejection for JMIR, this should be noted in the cover letter.**

Our requirements for submitted manuscripts are in accordance with the **Uniform Requirements for Manuscripts Submitted to Biomedical Journals**, drawn up by the International Committee of Medical Journal Editors (JAMA 1997;277:927-934 ). Please read these Uniform Requirements first, then read our complementing guidelines given below. The journal editor is member of the World Association of Medical Editors (WAME, www.wame.org), and the *Journal of Medical Internet Research* is committed to adhere to WAME's principles. The *Journal of Medical Internet Research* also supports and acts in line with the Editorial Policy Statements of the Council of Science Editors (http://www.cbe.org/services/draft_approved.cfm [Archived in WebCite]).

**Instructions for Authors of JMIR**

The *Journal of Medical Internet Research* (JMIR) is an innovative, international, peer-reviewed medical journal that aims to contain articles relevant for medical professionals, system developers, and system users alike. Instructions for authors are subject to frequent revision. Please look them over carefully before submission. See **Instructions for Authors** for further details on how to format your manuscript.

Note that since 2014 we require that all authors / coauthors to have an ORCID (a unique researcher identifier) at the time of publication. Application for an ORCID is free of charge and only takes a few minutes - please go to ORCID.org to apply for one. We also recommend that the corresponding author contacts all of his coauthors and encourages them to obtain an ORCID during the manuscript preparation process. While they can be added after submission, ORCIDs are required in case of acceptance.

Please review our Fee Schedule prior to submission. While some of our journals do not charge any fees, some others do charge.

**Submission Preparation Checklist**

As part of the submission process, authors are required to check off their submission's compliance with all of the following items, and submissions may be returned to authors that do not adhere to these guidelines.

1. The submission has not been previously published nor is it before another journal for consideration; or an explanation has been provided in Comments to the Editor. Related/overlapping published or submitted work will be uploaded as supplementary files so reviewers and editors can determine the degree of overlap with previous/other papers under consideration. Salami slicing of research is discouraged.

2. The submission file is in Microsoft Word (.doc/.docx) file format.

3. The text meets this journal's formatting requirements, in particular those summarized in the Author Checklist found in Instructions for Authors. The text employs *italics*, rather than underlining or bold as emphasis; with figures and tables (portrait only, no landscape format) placed within the text, rather than at the end. Additional information has been put in separate files to be uploaded as Multimedia Appendix.

4. I have read and understood the fee schedule. In particular, I understand and agree that unless my department/organization is a institutional member BEFORE submission (see dropdown-list in step 1 of the submission process), I/my department will be billed for the article processing fee (see Instructions for authors) in case of acceptance. PLEASE MENTION IN THE COVER LETTER ON SUBMISSION THAT YOU 1) AGREE TO PAY THE APF, OR 2) IF YOU THINK THAT THE APF SHOULD BE WAIVED DUE TO MEMBERSHIP OR FOR ANY OTHER REASONS. Journal sections marked with * may be eligible for a fee waiver or reduction under certain circumstances (must be justified in the comments field for the editor on submission). APFs may not apply for article categories marked with * (check instructions for authors). ** Special fees (in particular a submission fee) apply for research protocols and grant proposals. Note that the APF will also be billed if the author retracts the manuscript after acceptance, or if a case of scientific misconduct prevents us from publishing a manuscript after acceptance.

5. (please check this checkbox even if you do not wish to fast-track as an indication that you read this). I understand that if I wish to fast-track the paper, I will pay the Fast-Track-Fee immediately after submission (a payment link will be provided after submission) or at a later stage. The FTF guarantees an editorial decision within 15 working days (see website for further instructions)

6. I understand that all author names and their affiliations for the final publication will be taken from the database (metadata form), not the submitted manuscript, thus all author names must be entered in the metadata form during submission. Authors may remove author names from the manuscript if they prefer blind review. All coauthors have been/will be entered in the metadata form, and all coauthors fulfill ICMJE criteria in that they made 1) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; and 3) final approval of the version to be published. Authors should meet conditions 1, 2, and 3.

7. P-values are reported in accordance with our instructions for authors.

8. **\*For the month of July, 2019, the $90 submission fee for the *Journal of Medical Internet Research* will be waived\*** A submission fee of US $90 will be charged for all articles submitted to the *Journal of Medical Internet Research* (=this journal) EXCEPT letters or invited articles (there is no submission fee for sister journals -
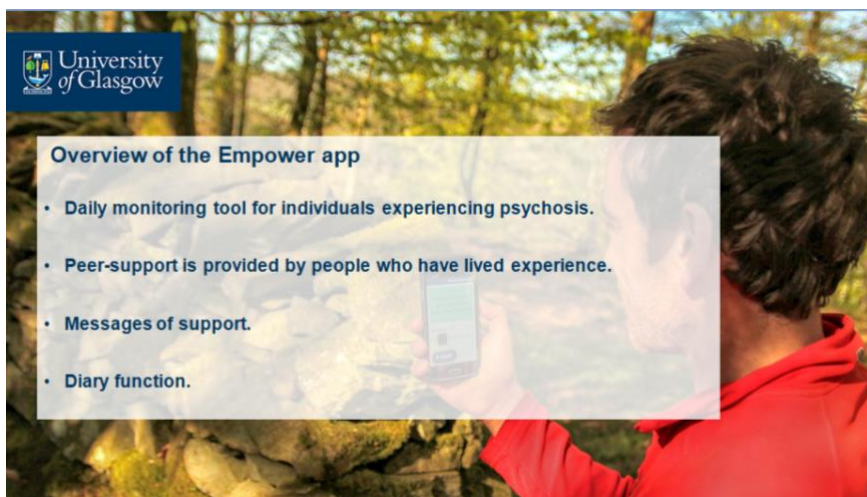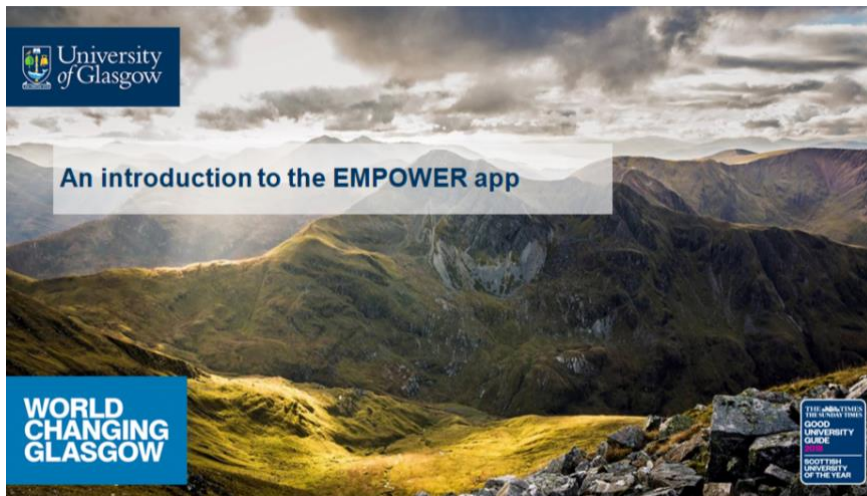
please change the journal in the drop down list above before proceeding). You can use Paypal or a credit card immediately after submission. Authors will not be able to complete the submission process without payment. This fee cannot be waived (only exception: invited articles), needs to be paid also by institutional members, and is non-refundable. This fee is in addition to other potential fees such as the optional fast-track fee (FTF) and the article processing fee (APF) for non-members. Authors should understand that the submission fee is non-refundable, even if the manuscript is promptly rejected without peer-review (we do send out the majority of papers for peer-review, but we reserve the right to reject papers without peer-review for any reason, including the topic not being deemed interesting enough, which is a subjective decision by the editor).

9. Authors agree that the manuscript and peer-review reports may be transferred to a JMIR sister/partner journal (e.g. i-JMR, JMIR Res Protoc, JMIR mHealth, JMIR Human Factors and others), if the paper is not found suitable for publication in JMIR, but is publishable in another journal. The submission fee for that partner journal (if any) will be waived, and transfer of the peer-review reports may mean that the paper does not have to be re-reviewed. Authors will receive a notification when the manuscript is transferred, and at that time can decide if they want to pursue publication in a sister/partner journal. If authors do NOT wish an automatic transfer to an alternative journal after rejection for JMIR, this should be noted in the cover letter.

## Appendix 2.2: Interview schedule

| Introduction/ orientation | Key aspects of the participation information sheet will be revisited. Informed Consent: <br> • confidentiality and its limitations will be discussed <br> • the participant will be reminded that they can take breaks, suspend and withdraw from the study <br> My role as the researcher will be briefly explored (e.g. ask questions/details). Purpose of the session - to gain your perspectives, thoughts and experienced. Expected timings (approx 1 hour) <br> Any questions? | |
|---|---|---|
| **Topic area** | **Questions** | **Further questions & prompts** |
| **Informal introduction** | Do you have a smart phone? | What do you use your smartphone for? Do you use apps? Which ones? <br> Do you use the internet or technology to access support for mental health? Any specific examples? <br> How have you found using technology for support? |
| **Experiences of getting support.** | How do you currently look after your mental health? | Do you have a self-management or crisis plan? <br> What things do you do to look after your mental health? |
| | Who do you get support from? | Do you get professional support? <br>   -How often do you see them? <br>   -How far away are your mental health team? Do you think this impacts on your wellbeing? <br>   -What does the support involve? <br>   -How did you find communicating with professionals who support you? <br><br> Do you get support from voluntary services? What does this involve? <br> Do you get support from family, friends or carers? <br>   -What does the support involve? |
| | When you have had difficulties with your mental health, how did you find accessing professional support? | Could you describe a specific example of this? <br><br> What helped you access support? <br><br> What gets in the way of you accessing support? |
| **Slides - description of EMPOWER App including its various functions, including daily monitoring tool, peer-support aspects, diary, charts and empower messages. A brief demonstration of the app will be given.** | |
| **Overall opinion of the app** | What are your initial thoughts on the app? | Are there any features you think would be helpful or not? <br> What might get in the way of you using the app? What might encourage you to use the app? <br> Given your previous experiences of seeking help, do you think this app would aid you in your recovery? |
| **Daily Monitoring** | What are you thoughts on using the app to monitor daily changes in aspects of your wellbeing? | Do you think you would use the daily monitoring feature? <br>   - What might get in the way of daily monitoring? <br>   - What might help you to do the daily monitoring? <br> What do you think about the monitoring information being shared and used to notify someone of changes in wellbeing? <br>   - What do you think are the benefits of this? <br>   - Do you have any concerns about this? <br> What do you think about the charts made from the monitoring information? <br>   - Do you think you would share these with other people (e.g. professionals, family)? <br>   - Possible benefits and/or concerns about this? <br> What do you think about the tailored messages produced from the monitoring information? |
| | What do you think about the role of a peer-support worker as part of the App? | Do you think this would be helpful? If so in what way? If not in what way? <br> What might encourage you to engage with a peer support worker? <br> Do you have any concerns about the role of a peer support worker? |
| | Is there anything else that you think is important that I haven't asked about? | |

**Appendix 2.3: Empower slides**

## Empower messages

## Flow of information

## Peer support

- People with lived experience are involved with providing support with the app.

- This can be practical and emotional support via phone calls and/or messages.

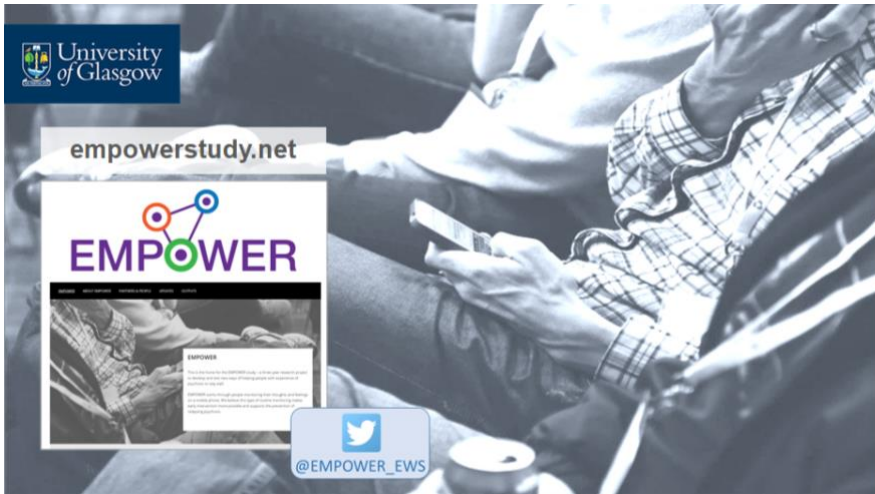- This support is tailored to your needs and wishes.

**Appendix 2.4: REC and NHS R&D approval**

**WoSRES**
**West of Scotland Research Ethics Service**

**NHS**
**Greater Glasgow and Clyde**

Mr Thomas Gilpin
Drumossie Unit
New Craigs Hospital
6-16 Leachkin Rd
Inverness
IV3 8NP

**West of Scotland REC 4**
Research Ethics
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ
(Formerly Yorkhill Childrens Hospital)

Date          12 November 2018
Direct line   0141 232 1808
E-mail        WoSREC4@ggc.scot.nhs.uk

Dear Mr Gilpin

**Study title:**        Service user experience of accessing support for psychosis in rural Highland and the potential use of Smartphone technology: an interpretive phenomenological analysis.
**REC reference:**      18/WS/0196
**Protocol number:**    N/A
**IRAS project ID:**    248816

Thank you for your submission of 12 November 2018. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 7 November 2018

**Documents received**

The documents received were as follows:

| Document | Version | Date |
|---|---|---|
| Letters of invitation to participant [Information leaflet for participant] | 0.3 | 08 November 2018 |
| Participant consent form [consent form] | 0.3 | 08 November 2018 |
| Participant information sheet (PIS) [Participation Information sheet] | 0.4 | 08 November 2018 |

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

| Document | Version | Date |
|---|---|---|
| GP/consultant information sheets or letters [GP letter] | 0.2 | 28 September 2018 |

| Document | Version | Date |
|---|---|---|
| Interview schedules or topic guides for participants [interview schedule] | 0.2 | 25 September 2018 |
| IRAS Application Form [IRAS_Form_08102018] | | 08 October 2018 |
| Letter from funder [Proceed to ethics University of Glasgow letter] | | 14 August 2018 |
| Letters of invitation to participant [Information leaflet for participant] | 0.3 | 08 November 2018 |
| Participant consent form [consent form] | 0.3 | 08 November 2018 |
| Participant information sheet (PIS) [Participation Information sheet] | 0.4 | 08 November 2018 |
| Research protocol or project proposal [Research proposal] | 0.3 | 28 September 2018 |
| Summary CV for Chief Investigator (CI) [Brief CV - Thomas Gilpin] | 0.1 | 28 September 2018 |
| Summary CV for supervisor (student research) [Summary CV Andrew Gumley] | | 28 September 2018 |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

| 18/WS/0196 | Please quote this number on all correspondence |
|---|---|

Yours sincerely

**Rozanne Suarez**
**REC Manager**

Copy to:    Ms Frances Hines, NHS Highland
            Professor Andrew Gumley, University of Glasgow
            nhsg.NRSPCC@nhs.net

Professor Angus Watson
Research, Development & Innovation Director
Research, Development & Innovation Division
NHS Highland
Centre for Health Science
Old Perth Road
Inverness
IV2 3JH

**NHS Highland**

Tel: 01463 255822
Fax: 01463 255838
E-mail: angus.watson@nhs.net

1st February 2019

NHS Highland R&D ID: **1453**
NRSPCC ID: **NA**

Mr Thomas Gilpin
Trainee Clinical Psychologist
New Craigs Psychiatric Hospital
Drumossie Unit
Leachkin Road
Inverness

Dear Mr Gilpin,

### Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled: 'Service user experience of accessing support for psychosis in rural Highland and the potential use of Smartphone technology: an interpretative phenomenological analysis. I acknowledge that:

- The project is sponsored by NHS Highland.
- The project has no external funding.
- Research Ethics approval has been awarded from **West of Scotland REC 4 (REC ref 18/WS/0196).**
- The project is Site-Specific Assessment exempt.

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with NHS Highland

**Headquarters:**
NHS Highland, Assynt House, Beechwood Park, Inverness, IV2 3HG

Chairman: David Alston
Chief Executive: Elaine Mead

- This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the UK Policy Framework for Health and Social Care Research (2018, V3.3 07/11/17), however prior written notice of audit will be given.
- Any researchers coming into NHS Highland for the purposes of carrying out research with patients will require a Letter of Access before starting the study at this site. Please contact Anna McIver (anna.mciver@nhs.net) for further assistance, if this is required.
- You are reminded that all amendments (minor or substantial) to the protocol and associated study documents or to the REC application should be copied to the NHS Highland Research and Development Office to obtain a R&D amendment approval letter. Guidance can be found at https://www.nhsresearchscotland.org.uk/services/permissions-co-ordinating-centre/permissions
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office. Please email documents to Anna McIver, RD&I Facilitator (anna.mciver@nhs.net).
- If applicable, monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month, to Debbie McDonald, RD&I Data Manager (debbie.mcdonald@nhs.net).
- Please report any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, frances.hines@nhs.net ).

Please quote your RD&I Highland reference number (Highland 1453).


Yours sincerely,



Frances Hines
RD&I Manager

cc     Frances Hines, R&D Manager, NHS Highland Research, Development & Innovation Division, Phase 3, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH

       Professor Andrew Gumley, University of Glasgow, andrew.gumley@glasgow.ac.uk


2

**Appendix 2.5: Consent form**

# Consent Form

**Research Study:** Service user experience of accessing support for psychosis in rural Highland and the potential use of Smartphone technology

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected.

☐

I understand that the researcher will have access to my personal details including my address so that he can send me a copy of the research findings. I understand my personal details will not appear in the research report.

☐

I understand that the interview will be tape recorded solely for the purposes of the research study as described in the Participant Information Sheet.

☐

I understand that the researcher may publish direct quotations, after the interview has been transcribed, and all names, places and identifiers have been removed.

☐

I give consent for the researcher to contact my GP, Psychiatrist and key worker to let them know of my participation in this study.

☐

I agree to take part in the above study.

☐

Name of Participant:                                Researcher:

Date:                                                       Date:

Signature:                                                Signature:

**Appendix 2.6: Information leaflet**

### Who will I see?

You will see the researcher, Thomas Gilpin.

Thomas will arrange to visit you in person or if this is not convenient arrange a discussion over the phone. This meeting will involve discussing what participation involves and answering any questions that you may have about the study. The researcher will provide you with a Participation Information Sheet.

Once you are satisfied that you have understood the study and what participation involves you can decide whether you want to take part or not. You are under no obligation to take part.

### Finding out more.

If you are interested in finding out more then you can either discuss it with the person who gave you this leaflet or contact the researcher using these contact details.

Phone: 01463 253697
Email: thomas.gilpin1@nhs.net

University of Glasgow

NHS Highland

V 0.3 08.11.18

# Take part in research about getting help for psychosis in rural communities.

RESEARCH

### What is the research about?

The study aims to understand the experience of accessing support for psychosis by individuals living in rural communities. We also want to explore people's opinions on the use of mobile applications as a tool to monitor symptoms and increase access to support.

If we learn more about the experiences of people accessing support and their opinions about using mobile applications, it may help us to plan further research on the helpfulness of mobile applications.

### What's involved?

Participants will take part in an interview with the researcher. This interview will in involve questions about your experiences and opinions.

To find out more about the study, the researcher will arrange a meeting to discuss the study in more detail with you. You are under no obligation to take part in the study

The study will not affect the care that you are receiving.

### Who is the researcher?

The researcher is a Trainee Clinical Psychologist and the study forms part of the Clinical Psychology training programme at Glasgow University.

### Why am I being asked to take part?

You have been identified by a keyworker as someone who is eligible to take part in the study.

V 0.3 08.11.18

**Appendix 2.7: Participation information sheet**

**Participation Information sheet**

I would like to invite you to take part in a research study. My name is Thomas Gilpin and I am a Trainee Clinical Psychologist. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read this Participation Information Sheet carefully and ask any questions that you might have.

**What is the research about?**

The aim of the study is to develop an understanding about people's lived experiences of accessing support for psychosis in rural Highlands. I am particularly interesting in identifying factors that improve and impede individuals accessing support in rural areas.

The research also aims to explore how people feel about the possible use of digital technology, for example the internet, mobile phones or Smartphone apps as a tool for increasing access to support for people living in rural locations. This study will focus on your thoughts on a Smartphone app.

**What are Smartphone apps?**

Apps, short for Applications, are tools on mobile phones that have different functions (e.g. games, monitoring activities, diaries). There are an increasing number of apps that aim to support people to manage their health.

**Why have I been asked to take part?**

We are asking people who have lived experience of psychosis and are living in a rural location to take part in this study.

**Do I have to take part?**

No, you do not have to take part in this study. It is completely up to you to decide whether or not you wish to take part. If you do not want to take part, it will not affect your routine treatment in any way. If you decide to take part you will be asked to sign a consent form. The consent form is a way of making sure you know what you have agreed to. If you decide to take part you are still free to withdraw from the study at any time and you do not have to give a reason for doing so.

**What will happen next?**

If you show interest in the study then I will arrange an initial meeting (either in person or over the phone). You are welcome to bring a friend, family member or a carer if this would make you feel more comfortable. At this meeting we will have a discussion about participation in the research, go through this Participation Information Sheet and complete a consent form.

**What does participation involve?**

At our first meeting I will answer any questions you may have. I will be asking if the meeting(s) can be recorded on a digital recorder. I will show you the equipment and demonstrate how it works before starting the recording. You are free to stop the recording at any time during the interview(s). I will then ask about your experience of psychosis and accessing support in a rural setting. These discussions usually last a hour but there is flexibility with this.

There are no right, or wrong, answers to any of the questions. It is your own experiences and thoughts that I am interested in.

**Why are the interviews being recorded?**

The interviews are recorded to allow me to carefully understand your experiences and our conversation. All information will be kept strictly confidential and will be stored on a password protected computer. I will write up every interview removing all identifiable information and will destroy the tapes afterwards. Quotations from the interview may be used in the report at the end of the study.

**What are the possible risks and disadvantages of taking part?**

It is not expected that the questions that will be asked will cause any significant distress or upset. However, there is a possibility that talking about past experiences of accessing support or other topics explored in the discussions may affect your psychological wellbeing. If you become upset or distressed by the study, the researcher will help you to access support from services if you think this is needed. In addition, you can take breaks, suspend discussions or end your participation at any time.

**What are the possible benefits of taking part?**

There are no direct benefits to you of taking part but you may find it beneficial to discuss your experiences in a non-clinical setting. The information we learn from this study may help to plan future research and develop new approaches to supporting people with psychosis living in rural settings.

**Will my taking part in this study be kept confidential?**

We will inform your GP, Psychiatrist and Keyworker that you have participated in the study.NHS Highland is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The information you provide will be treated confidentially and not shared with others. The information you give will be anonymised (e.g. using a ID number instead of your name). All recordings will be stored on a password protected computer. Your name and any information that could identify you will not appear in any reports or publications of the research. The researcher will access your personal details including your address so that he can send you a copy of the research findings. To safeguard your rights, we will use the minimum personally-identifiable information possible. All study data will be managed in accordance with the General Data Protection Regulation.

If you share information that makes the researcher concerned for your safety or the safety of other people, we may be required to tell others involved in your care (e.g. your Key Worker or Psychiatrist). We will always try to notify you beforehand if we are going to do this, and explain why.

You can find out more about how we use your information by contacting NHS Highland communications team on 01463 704723.

**What will happen to the results of the research study?**

You will be provided with a summary of the study. The final results and conclusions of the study will be published in a scientific journal and will form part of my qualification in Clinical Psychology.

**Who is organising the research?**

The research forms part of the Doctorate in Clinical Psychology course at the University of Glasgow.

**Who has reviewed the study?**

The study has been reviewed by Glasgow University to ensure that it meets important standards of scientific conduct and by NHS Highland Research Ethics Committee to ensure that it meets important standards of ethical conduct.

**What will happen if there is a problem or if I want to make a complaint?**

If you have any concerns about the study or the way it is conducted or if you want to complain about any aspect of this study, please contact NHS Highland Feedback Team at NHS Highland, PO Box 5713, Inverness IV1 9AQ.

**Can I speak to someone who is not involved in the study?**

Yes you can. Professor Hamish McLeod who is not involved in the study can answer questions or give advice about participating in this study. His telephone number is 0141 211 3920

**Thank you for reading this Participation Information Sheet.**

**Appendix 2.8: Excerpt of transcript and initial coding**

| 152 | P | Well erm I get some peer-support from the work here for instance. Erm… | Peer support |
|-----|---|-----------------------------------------------------------------------|--------------|
| 153 | R | So what does that look like? | |

| 154<br>155<br>156<br>157<br>158<br>159<br>160<br>161<br>162 | P | Well they, {voluntary support organisation} is a great place to talk and to exchange experiences and ideas you know and it can be actually quite uplifting we have lots of things happening on {island of residence}. {Voluntary support organisation} and couple of other initiatives that are supposed to help people's mental wellbeing so there's no shortage of opportunity to actually take part. I am also a volunteer with an advocacy group so I get involved in their report writing and their research, that's fine. I don't know if you could call that support but I guess it is in a way. | Great to talk and share experiences with peers<br><br>Third-sector involvement uplifting<br>Lots of initiatives going on island<br><br>Ample voluntary opportunities<br>Volunteer with advocacy group<br>Advocacy report writing and research involvement |
|---|---|---|---|
| 163 | R | How does that affect you, that peer support? | |
| 164<br>165<br>166<br>167<br>168<br>169<br>170<br>171 | P | Erm I think it's very valuable. I think, you know, speaking to someone who has had some of the same experiences as you or you speaking to someone else that is maybe going through a bad time, you know, and telling them about your experiences, it can be very valuable but I don't think it replaces professional help and yet I think a lot of reliance is placed on peer-support and third sector support you know people with mental health problems. It has its place but I don't think it ought to replace erm more mainstream mental health care. | Value of peer-support<br>Shared experience important<br><br>Talking to peers with similar experience valuable<br>Peer-support shouldn't replace prof help<br>Reliance on peer-support/third-sector<br>Peer-support shouldn't replace MH services |
| 172 | R | So you think there's more reliance on third-sector and voluntary services? | |
| 173<br>174<br>175<br>176<br>177<br>178<br>179<br>180 | P | Very much so yeah. I mean this isn't about me but but but what I have heard a lot is that if people have a spell in {MH hospital on mainland} when they come out again they don't come out to any sort of step down service they just come back {island} and they may not be 100% well at that stage but nothing, nothing is put in place by the mainstream erm mental health services to look after that person to transition back to {island} but they that job may well fall onto to services like {voluntary organisation} erm to try and ease that person back into society. | Lack of support for transition from inpatient to community<br><br>People not fully well on discharge from inpatient<br>Lack of community MH support<br><br>Voluntary organisations filling in the gaps of services<br>Voluntary services support transition back to community |
| 181 | R | Erm and how about wider family do they live in the area? | |
| 182<br>183<br>184<br>185<br>186<br>187<br>188<br>189<br>190 | P | I have a step-father who lives up in {northern village} in the north of the island and I think he is well aware, he would be very stupid if he wasn't aware that I had some sort of mental health problem but he is a bit old school and stigma is alive and well there and it's not something we discuss but I have. I also have a erm a very close friend who was my english teacher at school many many many moons ago, she's in her 90s now and at one stage when I was much younger in my teenage years I lived with her and her husband when I was going through a really bad spell. So we're still very much in touch and she's fully aware of my condition and that's nice. | Step-father lives nearby<br>Step-father aware of MH issues<br>Old school views<br>Stigma is alive<br>Stigma prevent discussions about MH<br>Very close friend nearby<br><br><br>Good to have friends fully aware of MH |
| 191<br>192 | R | And you mentioned that there is stigma and it's still very much alive, erm can you tell me a bit more about that? | |
| 193<br>194<br>195<br>196<br>197<br>198<br>199<br>200<br>201<br>202<br>203<br>204<br>205<br>206<br>207<br>208<br>209<br>210<br>211 | P | Yeah. It's err it's a funny mixture because there's all these initiatives about talking about you're mental health and those of us that have already put our heads above the parapet are very happy to talk about our mental health and you know you might you might think that the problem was over and then you try and organise a meeting in different villages on {island} erm to do with some sort of initiative you want to promote to help people's mental health and nobody turns up or one person turns up and they come in the back door so they won't be seen by the neighbours attending this meeting that had something to do with mental health you know. Same on {another island} we, with HUG action for mental health, we carried out some cafe conversation erm events where we wanted to get people talking about mental health and mental health services and we got quite a good crowd here but only because I work here and I, you know, I got together quite a good crowd in {main town on the island}. Two people up in {northern village} both of whom came in the back door. Nobody at all at {names two other villages} and we had the manager of the hotel where we were who came to talk. She didn't have any issues but | Mental health initiatives<br>Putting heads above the parapet by talking about MH<br>Happy to talk about MH<br>Stigma not gone<br><br>Organising initiatives to promote MH<br>People don't attend MH initiatives<br>People fear being associated with MH initiatives<br><br>Cafe conversation events<br><br><br><br>Attending MH events through the back door<br><br>Low attendance at MH event in smaller villages |

| 212 213 214 | | she knew what the issues were out there and she told us no nobody will come because nobody you know you've got this big feather flag here saying HUG action for mental health you know nobody will dare to come in that door because they might be seen by other people on the island. So you know it's pretty historic really in some ways. | Fear of being seen at MH event prevents attendance<br><br>Old fashioned views |
|---|---|---|---|

**Appendix 2.9: Excerpts from reflective diary**

**Process of coding**

I have just started coding the transcripts. I have read them a number of times and feel I am familiar with them now. I started the coding process and I am aware that I am maybe being a bit too interpretive in the initial stages. I think this is maybe due to me being immersed in the literature and my experience of rural life and supporting rural individuals. When I noticed that this was the case I took a break from the coding process and reviewed the steps in the Braun and Clarke book on completing successful qualitative research. Taking a step back and reflecting on what may be driving this initial interpretative stance, and reviewing the process outlined in Clarke and Braun (2006) helped me to strip the coding back to the data.

I am aiming to take an inductive approach in the analysis process and make sure the analysis comes from the data. I understand that the inductive-deductive concept is on a spectrum and that I will be bringing preconceived ideas but I will constantly review my stance and ensure the analysis can be consistently tracked back to the data - (Note: always review and try to keep an inductive approach to the coding and analysis).

How much are the codes being influenced by various factors - interviews with participant, emersion in the data, previous experiencing support rural people, discussions with staff about the research, reading the literature on the data, my experiences of accessing support? I will keep these in mind when developing the codes and themes.

I will discuss this with my research supervisor and see his perspective. My plan is to send the transcripts and codes to my supervisor to make sure that they are grounded in the data. I am also going to discuss the next process of developing the codes into a theme: What constitutes a theme? Frequency across participants Vs saliency of the codes/themes? Moving from coding to themes.

**Recruitment**
So I have started the process of recruitment, I expected that there may be difficulties with recruitment due to the hard-to-reach nature of the participants (e.g. significant distance to travel). One concern is a lack of clarity on a clear number about the potential participant pool due to a lack of a system within the NHS to identify participants that fit the criteria. I have started presenting the research project to the different services - I noticed that there was some apprehension from staff members about either participants' suitability or their capacity to identify participants. I completely understand how busy staff are and I will make sure that I highlight the ease of the recruitment process to ensure that they buy into the research. Also, I am concerned that recruiters may be excluding participants that they think might "not be able to engage or be interested in taking part in an interview". It is important to empower potential participants with the choice of participation within the limitations of capacity to consent.

Note: next time presenting the research highlight the importance of using the inclusion/exclusion criteria as an objective measure and ask participants even if they think they wouldn't be interested, to give them the opportunity.

**Appendix 2.10: Major research proposal**

# Major Research Project Proposal

**Matriculation number**:

**Academic Supervisor:** Professor Andrew Gumley

**Field Supervisor:**  Dr Clare Allot

**Date of Submission:** 21.05.18

**Version:** 3

**Word Count:** 2882

**Title:** Services users' experiences of accessing support for psychosis in rural Highland and the potential use of Smartphone technology: an interpretative phenomenological analysis.

**Abstract**

**Background**

Individuals experiencing psychosis in rural locations potentially face a number of additional difficulties, such as lack of public transportation, sparse support services, social isolation and increased stigma (Parr, Philo & Burns, 2004). The isolation associated with living in rural locations can lead to later detection of symptom changes, resulting in more severe symptoms by the time they access support (Kelly, 2003). Smartphone technology has the potential to increase access to support for people unable to easily access traditional support services (Ben-Zeev et al 2014).

**Aims**

The proposed research project aims to explore facilitating factors and barriers for individuals with psychosis accessing support within a rural location. Furthermore, the project aims to understand participants' perspectives on the possible use of Smartphone technology to increase access to support.

**Method**

In order to establish the experiences of service users and the meaning that is attached to them, an interpretative phenomenological analysis approach will be utilised to collect and interpret qualitative data. Semi structured interviews will be conducted with questions that focus on the above aims of the study.

**Applications**

A deeper understanding of participants' experiences could inform potential service adaptations and the use of Smartphone technology.

**<u>Background</u>**

Psychosis is a collective term used to describe conditions that affect the mind, where there has been some loss of contact with reality (Capps, 2010). The experience of psychosis is different for every individual. The condition is associated with distressing symptoms including changes in perception, hallucinations, delusions, apathy, incoherent speech and inappropriate behaviours. Over a lifetime, it is estimated that 1% of the population will experience psychosis (National Institute for Health and Care Excellence [NICE], 2014). The onset of the condition is associated with considerable negative effects on an individual's personal, social and occupational lives. This is exacerbated by significant societal stigma associated with the condition which can lead to further isolation and deterioration of wellbeing (Franz et al, 2010). In addition to the personal cost of psychosis, there is a significant financial cost for society and services associated with this condition, with estimates suggesting a yearly cost of £13.8 billion for the United Kingdom (Kirkbride et al, 2012).

A significant difficulty associated with psychosis is the issue of relapse. Approximately three quarters of individuals with schizophrenia will experience a relapse after achieving remission of symptoms (Brown et al, 2010). A number of factors have been identified that may increase the likelihood of relapse in psychosis, such as poor social integration (Drake et al, 2000) and unplanned disengagement from treatment (Robinson et al, 1999). A systematic review completed by Gumley et al (2014) identified that difficulties in developing relationships was associated with reduced engagement with health services, more problems with health staff, and increased frequency and duration of hospital stays. With such high rates of relapse associated with this disorder, it is important to utilise new and innovative ways to actively engage individuals in treatment to improve monitoring and early detection of symptom deterioration.

There has been a shift in policy towards utilising technology as a method to improve recovery, cost effectiveness, access and reduce waiting times (Department of Health, 2014). Emerging research has identified digital technology as an effective form of intervention that can improve positive psychotic symptoms, hospital admissions, socialisation, social-connectedness, depression, and medication adherence (Alvarez-Jimenez et al., 2012). Mobile use among individuals with psychosis is high, with around 69% of patients experiencing a first episode of psychosis owning an internet enabled Smartphone (Lal et al, 2015). With Smartphone use so high, this provides an opportunity to utilise this technology

as a strategy to increase access to support. There has been growing evidence on the use of Smartphone applications in the management of psychotic symptoms. Ben-Zeev et al (2014) researched the feasibility of a Smartphone application used in the monitoring of symptoms for individuals experiencing schizophrenia. They reported high levels of satisfaction and usability from participants, with adherence to daily monitoring over 85%. Furthermore, due to the mobility of Smartphone applications and other forms of digital technology, interventions delivered in this format have been identified as a specific strategy that can aid the support of individuals with mental health difficulties in rural and remote regions (Farrell & McKinnon, 2003).

Individuals experiencing mental health difficulties in rural areas face a particular set of difficulties due to their remote location that may exacerbate mental health issues. These include lack of public transportation, sparse support services, social isolation and increased stigma (Parr, Philo & Burns, 2004). The isolation of rural communities can be a barrier to services and leads to later detection of psychosis and engagement with mental health support (Kelly, 2003). Consequently, individuals may have more severe symptoms by the time they access support. As there are additional difficulties associated with the rural aspects of living, it is important that tailored healthcare approaches are adopted. The most recent Scottish mental health strategy outlined the importance of addressing issues associated with rural living to reduce isolation and improve access to health care to maintain good physical and mental wellbeing (The Scottish Government, 2017).

Although limited, there are a growing number of qualitative studies on the perspectives of service users and families on the use of Smartphone apps and internet based interventions in the management of psychosis. This research suggests that this method of support is well received and can be a helpful approach in increasing access to support (Aref-Adib et al, 2016; Palmier-Claus et al, 2012). There lacks qualitative research on the perspectives of individuals living in rural areas of Scotland utilising mental health services. An experiential exploration of the perspectives of people living with psychosis in rural settings in the Highlands will provide invaluable insights on current health support experiences and the possible use of Smartphone technology. This could inform the possible incorporation of Smartphone technology into the care packages of individuals living with psychosis in rural locations.

**Plan of investigation**

**Aims**

The study aims to gain a deeper understanding of the perspectives of service users in rural locations who have experienced psychosis. Specific details on current barriers and facilitators to accessing support and use of health services will be explored. Furthermore, the service users' perspectives on the possible use of Smartphone technology as a tool in their recovery will also be explored.

**Inclusion criteria**

Participants must be living in a rural location within the Highlands. This is defined as a population of 3,000 or less (Scottish Executive, 2004). They must be able to understand and communicate in English. They must also fulfil the ICD-10 (World Health Organisation, 1992) diagnostic criteria for schizophrenia, schizotypal and delusional disorders (F20-29), mania with psychotic symptoms (F30.2), bipolar affective disorder (F31.2, F31.5) or depression with psychotic symptoms (F32.3, F33.3). After obtaining consent from the participant, the researcher will communicate with appropriate medical professionals to confirm any diagnosis. Additionally, the study will be discussed with a key worker or medical professional to identify if they have any concerns about clinical risk or possible detrimental consequences from participating. If the professional believes the study may have a negative impact on a participant's wellbeing or treatment, they will be excluded from the study.

**Exclusion criteria**

Individuals who are under the age of sixteen, live in an urban area, have a learning disability, are in an acute psychotic episode or do not have the capacity to give informed consent will not be recruited into the study.

**Recruitment**

Participants will be recruited by clinical staff from the rehabilitation service and local community mental health teams. Individuals will be purposively recruited from rural areas within the Highlands. Information leaflets will be circulated to relevant clinical staff in different geographical areas that have access to potential participants. Clinical staff can then pass on the information about the study and the researcher's contact details. Those who

express interest in the study will be provided with an information pack containing further details on the research. Informed consent will be obtained before the study takes place. I will write to the participant's general practitioner, psychiatrist and a key worker to inform them of the individual's participation in the research. Written informed consent forms will be completed before each recorded interview to ensure the participant is aware they can withdraw from the study at any point.

**Interview Procedure**

Data will be collected through semi-structured interviews with participants. Initially, information about access and experiences of mental health services will be gathered. The participants' perspectives on the possible use of Smartphone technology as a method of monitoring symptoms and increasing access to support will be explored. The questions will be open-ended to encourage rich and full responses from participants. The researcher will take an inquisitive stance and utilise flexibility with follow-up questions to encourage further dialogue. During interviews, the researcher will try to establish a rapport with participants to make them feel comfortable and hopefully obtain more honest perspectives and a deeper understanding of their experiences.

Participants will be interviewed within NHS or social care premises. If this is not possible, home visits will be used following a thorough health and safety assessment. Participants will be informed on a number of occasions that they can stop the interview at any point and can take a break and return to the interview at a later date. A flexible approach to interviews will be taken to work around the needs of the participants. Participants may be interviewed more than once if it is deemed that this may lead to further detail on their experiences. Interviews will last roughly one hour. Interviews will be completed using a university issued Dictaphone.

**Sample Size**

The exact number of participant cannot be predicted as it will be determined by availability and recruitment. The aim is to recruit between eight and twelve participants for the study. This is in-line with recommendation for the appropriate number of participants for an Interpretative Phenomenological Analysis (IPA) based qualitative study on the Clinical Psychology Doctorate in the United Kingdom (Turpin et al, 1997). This provides sufficient

data to identify similarities and differences between participants, without the researcher becoming overwhelmed by information.

**Data Analysis**

IPA aims to explore how people make sense of their experiences and their perspective on a given aspect of their life. IPA has an emphasis on sense-making by both participants and researcher, meaning that it can be described as having cognition as a central analytic concern. Smith (2015) provides a six stage framework that the researcher will utilise when completing IPA. It is recommended that researchers fully immerse themselves in the data. Initially, each interview and subsequent transcript will be reviewed on a number of occasions to become familiar with the content. During this process, notes will be made on linguistic, descriptive, and conceptual content. These exploratory notes will be analysed to identify any emerging themes. After this, the researcher aims to make connections and group emerging themes based on conceptual similarities. Then theme patterns across participants will be considered, identifying key themes that incorporate the overall experiences of participants. An independent researcher will examine a number of randomly selected transcripts to verify themes and ensure key conceptualisations have not been missed.

**Health and safety issues**

To ensure the safety of participants and researcher, interviews will take place in NHS or social care buildings during working hours. If this is not possible home visits may be necessary following a thorough health and safety assessment. Local NHS policies will be followed during data collection. Participant's comfort and wellbeing will be assessed before and after the interview process to ensure any possible distress is monitored and managed appropriately. If there are high levels of distress the interview will be suspended and the researcher will stay with the participant until the distress reduces. If the distress does not reduce, assistance will be sought from other clinical staff. If a participant discloses any issues relating to risk to self or others during our meetings, then local NHS risk management policies will apply.

**Ethical Approval**

A number of ethical issues will be considered as the research involves possibly vulnerable individuals due to their mental health difficulties. The British Psychological Society (BPS)

has provided guidelines on important ethical principles to follow when completing research. These include obtaining full informed consent, no deception of participants, maintaining confidentiality of participant data and the prevention of any possible harm to participants. The project will be submitted to NHS Highland Research and Development Department for approval. Data collection, storage and analysis will occur while following the good practice principles of the Data Protection Act (1998), NHS Highland and the University of Glasgow guidelines. Caldicott guardianship approval will be sought through NHS Highland to ensure all aspects of data collection, storage and confidentiality has been considered.

**Financial issues**

The costs will include stationary for recruitment packs containing initial information sheets and consent forms. A recorder will be required to tape the interviews.

**Timetable**

Ethics submitted: August 2018

Recruitment: September 2018 - December 2018

Interviews conducted: December 2018 - March 2019

Analysis: March - May 2019

Submission: July 2019

**Practical applications**

It is hoped that the study will help develop an understanding of the perspectives of service users with psychosis in rural settings on current facilitators and barriers to accessing support and the potential use of Smartphone applications in the support of psychosis. The qualitative data collected in the study could be used to inform potential service changes to increase access to support for individuals living with psychosis in rural Highlands.

**References**

Aref-Adib, G., O'Hanlon, P., Fullarton, K., Morant, N., Sommerlad, A., Johnson, S, & Osborn, D. (2016). A qualitative study of online mental health information seeking behaviour by those with psychosis. *BMC Psychiatry,* 16:232.

Alvarez-Jimenez, M., Gleeson, J. F., Bendall, S., Lederman, R., Wadley, G., Killackey, E., et al. (2012). Internet-based interventions for psychosis: a sneak-peek into the future. *Psychiatry Clinics of North America*, 35, 735–747.

Ben-Zeev, D., Brenner, C.J. Begale, M., Duffecy, J., Mohr, D.C., & Mueser, K.T. (2014) Feasibility, Acceptability and preliminary efficacy of a smartphone intervention for schizophrenia. *Schizophrenia Bulletin*. doi:10.1093/schbul/sbu033

Birchwood, M. (2003). Pathways to emotional dysfunction in first-episode psychosis. *British Journal of Psychiatry*, 182, 373–375.

Brown. S., Kim. M., Mitchell. C. & Inskip, H. (2010) Twenty-five year mortality of a community cohort with schizophrenia. *The British Journal of Psychiatry,* 196, 116–121.

Capps, D. (2010). Understanding Psychosis: Issues, Treatments, and Challenges for Sufferers and Their Families. UK: Plymouth, Rowman & Littlefield Publishers Inc.

Department of Health (2014). Closing the Gap: Priorities for Essential Change in Mental Health. Department of Health.

Drake, R. J., Haley, C. J., Akhtar. S. & Lewis, S. W. (2000). Causes and consequences of duration of untreated psychosis in schizophrenia. *The British Journal of Psychiatry,* 177, 511–515.

Farrell, S. P., and McKinnon, C. R. (2003). Technology and Rural Mental Health. *Archives of Psychiatric Nursing,* 17:1.

Franz, L., Carter, T., Leiner, A. S., Bergner, E., Thompson, N. J., & Compton, M. T. (2010). Stigma and treatment delay in first-episode psychosis: a grounded theory study. *Early Intervention in Psychiatry*, *4*(1), 47–56.

General Register Office for Scotland. Occasional Paper No.11. Scotland's Census (2005). Statistics on Migration. Available at: http://www.gro-scotland.gov.uk/statistics/theme/migration/census2001-migration- stats/.

Gumley A, Taylor H, Schwannauer M, Macbeth A. (2014) A systematic review of attachment and psychosis: Measurement, Construct Validity and Outcomes. *Acta Psychiatrica Scandinavica* 129, 257-274. doi:10.1111/acps.12172

Kelly, M. (2003). The Identification of the Duration of Untreated Psychosis in a Sample Population of Individuals with a First Episode of Psychosis in East Dorset. Dorset Healthcare NHS Trust, Poole.

Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, D., Boydell, J, et al. (2012). Incidence of Schizophrenia and Other Psychoses in England, 1950–2009: A Systematic Review and Meta-Analyses. *PLoS ONE*, 7(3).

Lal. S., Dell'Elce, J., Tucci, N., et al. (2015). Preferences of young adults with first-episode psychosis for receiving specialised mental health services using technology: a survey   study. *Journal of Mental Health*, **2**(2): e18.

National Institute for Health and Care Excellence (2014). Psychosis and schizophrenia in adults: prevention and management. Available at https://www.nice.org.uk/guidance/cg178.

Palmier-Claus, J., Ainsworth, J., Machin, M., Barrowclough, C., Dunn, G., Barkus, E., Rogers, A., Wykes, T., Kapur, S., Buchan, I., Salter, E. & Lewis, S (2012). The feasibility and validity of ambulatory self-report of psychotic symptoms using a smartphone software application. BMC Psychiatry, 12, 172.

Parr, H., Philo, C. & Burns, N. (2004). Social geographies of rural mental health: experiencing inclusions and exclusions. *Transactions of the Institute of British Geographers*, 29:4, 401 - 510.

Robinson, D., Woerner, M. G., Alvir, J. M., Bilder, R., Goldman, R., Geisler, S., Koreen, A., Sheitman, B., Chakos, M., Mayerhoff, D. & Lieberman, J. A. (1999). Predictors of relapse following response from a first episode of schizophrenia or schizoaffective first  disorder. *Archives of General Psychiatry*, 56, 241 - 247.

Scottish Executive (2004). Annual Rural Report. *Scottish Executive,* Edinburgh.

Smith, J.A., & Osborn, M. (2003). 'Interpretative phenomenological analysis, in J.A. Smith  (ed.), Qualitative Psychology: A Practical Guide to Research Methods (pp.51-80). London: Sage.

The Scottish Government (2012). Rural Scotland Key Facts. [Online]; Available at: http://www.scotland.gov.uk/Publications/2012/09/7993/0.

Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J.A., Walsh, S. (1997). Standards for  research projects and theses involving qualitative methods: suggested guidelines for trainees and courses. *Clinical Psychology Forum*, 108, 3-7.