# Service User Experiences of Peer Support in an Adult Community Mental Health Service: An Interpretative Phenomenological Analysis

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#### **Thesis Abstract**

This thesis explores the experiences of individuals who have received mental health peer support (PS) within a National Health Service (NHS) adult community mental health team. PS is increasingly popular in mental health services in the United Kingdom; however, there is not yet a well-developed evidence base. Literature pertaining to the experiences of those who receive PS is particularly limited, and therefore research has tended to overlook what matters to recipients themselves.

The purpose of the research study was to explore how individuals in receipt of PS made sense of their experience, and what they found most helpful.

NHS and local ethical approval was granted. Peer support workers were asked to suggest potential participants who fulfilled the inclusion criteria. Five participants were interviewed using open-ended, semi-structured interviews. Verbatim transcripts were analysed using Interpretative Phenomenological Analysis.

Analysis of transcripts resulted in 3 super-ordinate themes, in which a period of reflection on identity and relationship preceded a period of more active, outwardly observable change. The first theme, *power of relationship*, reflected participants' experiential accounts of a felt sense of emotional safety, a sense of equality and a feeling of hope, arising out of the sharing of lived experience. The second theme, *focus on change*, highlighted the importance to participants of a shared commitment to sustained positive change, through advocacy to mental health teams, role-modelling and the sharing of knowledge. The final theme, *psychological impact*, reflected an increased desire for social connection and contribution. The findings support the centrality of relationship over "intervention", and suggest that both models of PS and future service evaluations incorporate recipient experience.

## Acknowledgements

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# **Contents**

List of tables	5
List of figures	5
List of appendices	5
Systematic Narrative Review	6
Bridging Section	61
Empirical Research Paper	62
Additional Chapters	
Extended Methodology	105
Discussion and Critical Evaluation	130
Appendices	157

List of Table	s: Systematic Narrative Synthesis						
Table	1: Descriptive Characteristics of Selected Articles	30					
Table 2: Table of themes							
List of Figure	es: Systematic Narrative Synthesis						
Figure	e 1: Search Strategy	17					
Figure	2: Search Process for Identifying Relevant Papers	22					
List of Table	s: Original Research Paper						
Table	1: Sample characteristics	71					
List of Figure	es: Original Research Paper						
Figure	1: Hierarchy of super-ordinate and ordinate themes	75					
List of Appe	ndices						
Appendix A:	Quality appraisal of selected articles and CASP scores	158					
Appendix B:	Data extraction Forms:	159					
	I: Summary Characteristics of Selected Article.						
	II: Table of Key Findings and Supporting Data extracts						
Appendix C:	Semi-Structured interview schedule	176					
Appendix D:	Letter of introduction	178					
Appendix E:	Participant information sheet	179					
Appendix F:	Consent form	184					
Appendix G:	Demographic information form	185					
Appendix H:	Study poster	187					
Appendix I:	NHS ethical approval	188					
Appendix J:	Local NHS Trust R&D approval	192					
Appendix K:	Author Guidelines: Qualitative Health Research (QHR)	193					

A Systematic Narrative Synthesis of Service User Experiences of Peer Support
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A Systematic Narrative Synthesis of Service User Experiences of Peer

Support

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7

#### **Abstract**

Peer support interventions are being rolled out across mental health services in the UK. Although there is preliminary evidence to support the palatability and usefulness of peer support in mental health, there is not yet a well-developed evidence base. There is heterogeneity in how peer support is provided within mental health services, and debate about the nature of its underlying mechanisms. While peer support initiatives are increasingly popular, there is limited understanding of how service users receive and perceive peer support. This qualitative narrative synthesis integrates the findings from the available qualitative and mixed methods literature to look at how peer support is perceived and received by service users. It is hoped that this will shed light on what is experienced as useful within peer support by those who receive it, and in doing so potentially inform future interventions and models.

141 words.

#### Introduction

# **Peer Support**

Within the UK, mental health services are becoming increasingly recoveryoriented (Department of Health, 2009), and the active involvement of individuals with personal experience of mental illness and recovery to provide interventions to service users who are at an earlier stage in their recovery, known as 'peer support' (PS), is a key part of this strategy (Davidson, Chinman, Sells & Rowe, 2006). Peer support (PS) can take various forms including self-help groups (Hardiman & Segal, 2003; Kennedy & Humphreys, 1994), clubhouses (Macias, Jackson, Schroeder, & Wang, 1999), and casual support (Davidson, Chinman, Sells & Rowe, 2006), and varies in terms of the type of support offered (listening, mentoring, education, social and practical support), and how structured the intervention is, whether the support is delivered individually or within a group setting, and the types of settings in which it occurs (in-patient units, out-patient clinics, community- or home-based interventions), and the service structures within which it operates (statutory services, voluntary or partnership organisations). In addition, those delivering PS, while all having in common the experience of mental illness and using services, vary in terms of the degree of formalised training they will have undertaken, and whether or not they are formally employed and paid.

More formalised programmes of PS of the type delivered in statutory services by trained, formally paid individuals employed as 'peer support workers' (PSW), are currently well supported in the NHS largely because they are compatible with recent mental health policy that emphasises self-management and the patient as expert (Shepherd, Boardman, & Slade, 2008). Indeed, PS of this type is cited throughout

many developed nations as desirable best practice (e.g., Medicaid, 2007; Mental Health Commission of Canada, 2016; Mental Health Coordinating Council (Australia), 2011). Furthermore, the formal employment of former service users as PSW is supported by an implementation programme that seeks to identify and develop new roles for those with experiential knowledge (Borkman, 1976) or "lived experience" within mental health services, as opposed to solely professional knowledge, and it is argued that there are benefits not only for service users but to staff and to the organisation via improving organisational culture, and improving service user involvement (Repper & Perkins, 2013).

Common to all descriptions of PS is the idea that people who have experienced mental health difficulties may use their personal experiences or so-called 'livedexperience' of mental illness to provide support, hope and encouragement to others going through similar difficulties (Solomon, 2004; Davidson et al., 2006). Such individuals are, it has been argued, better able to relate to others in a similar situation, and do so because of their lived experience, which directly informs their interactions with the person they support (MacNeil & Mead, 2005). It has also been argued that the sharing of lived experience (or 'disclosure') as an integral part of PS, challenges internalised negative or self-stigmatising beliefs as hypothesised in a recent paper examining the link between use of mutual help programmes and quality of life measures (Corrigan, Sokol, & Rüsch, 2013). Beyond disclosure, there exists some consistency within the literature around the importance for successful PS of repeating themes of connectedness, mutuality and role-modelling built on shared experience (Repper & Carter, 2011), while Mead, Hilton & Carter (2001) describe the importance of "empathic understanding through shared experience", arguing that PS should be founded on "mutual respect, shared responsibility and a shared agreement of what will be helpful" to both parties (p. 135). These hypothesised elements may end up being important in terms of developing a descriptive and explanatory model of PS, although their centrality to a possible PS mechanism is as yet relatively untested.

#### The Evidence Base

Literature reviews and meta-analyses of peer-support demonstrate how PS research has developed focussing first on the feasibility of employing peers to deliver support interventions (Davidson et al., 2006), to the broader challenges of implementation of PS within organisations and its benefits (Repper & Carter, 2011), to comparison studies focussing on effectiveness (Lloyd-Evans, et al., 2014), to latterly the shift towards identifying the "active ingredients" and mechanisms of action of PS (Davidson, Bellamy, Guy & Miller, 2012). One recent review (Chinman et al., 2014), looked at 20 studies of PS, and evaluated the evidence for outcomes for peers delivering manualised interventions, peers added to traditional services, and peers recruited into existing clinical roles, and found mixed results, with some studies reporting peers delivering better outcomes while one study reported a negative outcome. Comparisons were not straightforward, and there were methodological difficulties with several of the studies. Outcome measures were varied, perhaps because what to measure remains a source of on-going debate, which in turn makes the focus on building a meaningful evidence base complicated.

One early review (Salzer, Shear & Liptzin, 2002) called for an appreciation that PS was sufficiently different from traditional mental health interventions as to require "unique approaches to how they are studied", and called for more systematic research studies and increased use of randomisation and control to achieve the title of being "evidence-based".

For instance, two recent meta-analyses of PS effectiveness studies (Lloyd-Evans et al., 2014; Pitt et al., 2013), did indicate that PS performs equitably with non-peer social interventions, but neither engaged with the methodological issue whether randomised control trials are appropriate means of studying what are naturally heterogeneous and complex psychosocial interventions. Such reviews are influential however to policy and decision-making relating to service design and treatment choice because of their high position in hierarchies of levels of evidence (Noyes & Lewin, 2011). Therefore, in reflecting on what is meant by "evidence-based" in relation to recovery-focussed interventions such as PS, there exists a clinical argument for increased plurality in research designs in addition to a commitment to conceptualising PS in a meaningful and flexible manner.

The issue of "evidence-based" approaches also gets to the heart of the issue of patient involvement and choice in mental health. With the paradigm shift towards recovery, patients are becoming more involved in co-production and facilitation of interventions meaning that over time different conversations may need to emerge between healthcare professionals and their patients reflecting this shifting power dynamic about treatment, choice and recovery. Issues of mere effectiveness may be secondary to acceptability and a willingness to try approaches that work in ways that are more challenging to evaluate. The implementation of PS within mental health services both in the United Kingdom and abroad (in particular the United States, New Zealand, Australia and Canada) has been relatively rapid and, as Davidson et al., (2006) argue, has outstripped the rate at which the evidence-base has expanded. However, while a lack of evidence could undermine arguments for PS in mental health, it is important that care is taken to use a balanced range of designs and methodologies, including qualitative approaches. In this way, an evidence base can be

built that is more reflective of the complexity of this contextualised, psycho-social intervention.

# **Qualitative Reviews of Peer Support**

There are many qualitative studies within PS even if these are underrepresented in the review literature. Qualitative designs are typically better suited to exploring the types of complex interpersonal, subjective processes which may underpin peer-support and can help to increase insight into the variation in outcomes across existing studies. It may be that difficult to measure, inter-personal elements of peer-support may be most susceptible to context and variation and may therefore impact varyingly on later more measurable outcomes. Earlier reviews such as Davidson et al.'s (1999; 2006) provided useful and insightful narrative evaluations of the research base and key issues, although both are now over ten years old. A more recent qualitative meta-summary of PS research (Walker & Bryant, 2013) presented summarised qualitative findings of 25 studies (mixed-methods and qualitative) from a range of perspectives (organisational, PSW and service users) that used a range of analytical methods. Hope was cited as a major process outcome in PS, consistent with the existing literature, and the review also presented data suggesting that the concept of "role-modelling" may not be a universal experience, which was a welcome insight. However, the review was arguably limited by its synthesis method (Sandelowski & Barroso, 2006), which is designed to put numerical values on qualitative data, but summarising to this extent results in a loss of data, context and meaning. Furthermore, only four studies directly involved service-users and so the majority of service-user related findings presented in the review were in fact secondary interpretations from PSW and clinical staff about service user experience of PS. It is therefore unknown to

what extent their impressions were representative of actual service user experiences and priorities.

The reasons behind the lack of studies directly involving service users may be due to difficulties in recruitment, a tendency to carry out studies not requiring lengthy ethics approval using staff members or because service users are reluctant to engage with research about PSW with whom they may have developed close relationships. However, recent health policy has stated that "any attempt to judge the quality of health services would be incomplete without considering the experiences of people who use them" (NICE, 2012). Therefore, such obstacles should be overcome wherever possible, and a pragmatic determination to develop research programmes involving service users could indeed be another occupational route to assist recovery along with becoming a PSW.

Finally, another limitation of the Walker and Bryant review was that the authors did not overtly engage with the well-known issues relating to systematic search strategies and locating qualitative literature. They do however report some hand-searching was needed but does not elaborate on how this was carried out. The search was also carried out on articles up to 2010, and therefore there is an argument that an updated and methodologically developed replication of this review is due.

This review will aim to provide an up-to-date review of qualitative literature but with a focus solely on the perspectives of recipients of PS, rather than staff or PSWs. Given that peer support interventions are provided in heterogeneous and complex contexts, and the mechanism of peer support is likely to be a complex contextualised interpersonal process, this review will aim to include contextual issues in order to create more valid understandings of peer support.

It is hoped that the review will provide a useful and complementary understanding to what is already known about PS, and will provide a means to highlight future avenues of research and the development of explanatory models that encompass the experiences of all those involved.

## **Review question**

What do qualitative studies tell us about the active ingredients of PS from the perspective of the recipients of PS services?

#### Method

#### Inclusion criteria

The review focused on adults who received mental health PS in statutory, voluntary or mixed/partnership settings. Studies including recipients with dual-diagnosis were included. Types of studies included were limited to those that used qualitative methods for data collection and analysis, including mixed-methods studies, and that presented at least some results of analysis in narrative form (e.g., first-person quotes) on the experiences and views of adult recipients of PS. Types of data collection methods included verbal interviews, focus groups, or free-form textual information from surveys and questionnaires. Articles in which recipient data was presented as well as data from other perspectives were included.

Mental health PS was defined as any individually delivered intervention presented face-to-face by a PSW to a recipient, including emotional, psychoeducational and/or practical support, including recovery-focussed manualised interventions. Non-English language studies were considered if an English translation

was also available, and articles were not limited by geographical region. Grey literature was searched.

#### **Exclusion criteria**

Studies were excluded that focused solely on other perspectives of the PS experience, such as services, PSW or carers. Studies were excluded for settings that were purely peer-led, or mutual-aid organisations such as drop-in centres. No group PS studies were included, and studies focussing solely on substance-abuse PS were also excluded. All other health-related, non-mental-health peer-support studies were excluded.

# **Search Strategy**

An initial top-down search was undertaken, followed by an iterative, bottomup, hand search. The initial search was conducted in November 2016, and focused on
articles published between 1990 and the end of November 2016, from the following
on-line databases: CINAHL Complete [EBSCO], AMED, PsychINFO [EBSCO],
PsychArticles (EBSCO), MEDLINE complete [OVID]. The search strategy used was
based on that designed and by Simpson, Barkham, Gilbody & House (2003) and Pitt et
al., (2013) in their Cochrane reviews of service-users as providers of care in statutory
mental health settings, using their terms. For example, subject-specific terms, e.g.,
(peer or mutual) adj (support\* or counsel\* or specialist\*), setting-specific terms, e.g.,
(exp mental health services/ community mental health/), and population-relevant
terms, e.g., (patient\* or client\* or user\* or service user\* or consumer\* or mental health
consumer\* or survivor\* or people\* or people with mental illness). This search was
combined with a comprehensive list of qualitative search terms designed by
Sandelowski & Barroso, (2006) updated by the addition of interpretative

phenomenological analysis as a qualitative method (e.g., "content analysis/ or thematic analysis/ or interpretative phenomenological analysis").

Figure 1: Search Strategy

- S1 MH mental health services+
- S2 MH psychotherapy+
- S3 MH psychiatry+
- S4 MH psychiatric service+
- S5 MH psychiatric units
- S6 MH psychiatric nursing+
- S7 MH hospitals, psychiatric
- S8 MH substance use rehabilitation programs+
- S9 MH mental disorders+
- S10 MH psychiatric patients+
- S11 mental\* ill\* or mental disorder\* or mental disease\* or mental health\* or mental patient\* or mental hospital\*
- S12 psychiatric ill\* or psychiatric disorder\* or psychiatric disease\* or psychiatric health\* or psychiatric patient\* or psychiatric hospital\* or psychiatric treatment
- S13 chronic\* mental\* or chronic\* psychiatric\* or severe\*mental\* or severe\* psychiatric\* or serious\* mental\* or serious\* psychiatric\*
- S14 s1 or s2 or s3 or s4 or s5 or s6 or s7 or s8 or s9 or s10 or s11 or s12 or s13
- S15 consumer advoca\* or patient advoca\*
- S16 MH consumer organizations+
- S17 MH mental health organizations+
- S18 (involv\* or inclusion or participati\* or collaborati\*) and (patient\* or inpatient\* or outpatient\* or client\* or user\* or service user\* or consumer\* or mental health consumer\* or survivor\* or people\*)
- S19 MH peer group
- S20 (peer or mutual) adj (support\* or counsel\* or specialist\*),
- S21 assertive community treatment
- S22 s15 or s16 or s17 or s18 or s19 or s20 or s21
- S23 provide\* or staff\* or employ\* or case manag\* or (service\* N4 deliver\*) or collaborator\* or aide or aides or specialist\* or consultant\* or personnel
- S24 s22 and s23
- S25 TI (patient\* or inpatient\* or outpatient\* or client\* or user\* or service user\* or consumer\* or mental health consumer\* or
- survivor\* or people\* or people with mental illness) and TI (provide\* or service provider\* or staff\* or team\* or personnel or
- employ\* or case manag\* or service delivery or collaborat\* or aide or aides or specialist\* or consultant\* or delivered or operated or assisted or led or managed or conducted or directed or run)
- S26 AB (user\* N2 provide\*) or AB (user\* N2 service provide\*) or AB (user\* N2 staff\*) or AB (user\* N2 team\*) or AB (user\* N2 personnel) or AB (user\* N2

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employ*) or AB (user* N2 case manag*) or AB (user* N2 service delivery) or AB
(user* N2 collaborat*) or AB(user* N2 aide) or AB (user* N2 aides) or AB (user* N2
specialist*) or AB (user* N2 consultant*) or AB(user* N2 delivered) or AB (user*
N2 operated) or AB (user* N2 assisted) or AB (user* N2 led) or AB (user* N2
managed) or AB (user* N2 conducted) or AB (user* N2 directed) or AB (user* N2
run)
S27 AB (consumer*N2 provide*) or AB (consumer*N2 service provide*) or AB
(consumer*N2 staff*) or AB (consumer*N2 team*) or AB (consumer* N2 personnel) or AB
(consumer* N2 employ*) or AB (consumer* N2 case manag*) or AB (consumer* N2 service
delivery) or AB (consumer* N2 collaborat*) or AB (consumer* N2 aide) or AB (consumer* N2
aides) or AB (consumer* N2 specialist*) or AB (consumer* N2 consultant*) or AB
(consumer* N2 delivered) or AB (consumer* N2 operated) or AB (consumer* N2 assisted) or
AB (consumer* N2 led) or AB (consumer* N2 managed) or AB (consumer* N2 conducted) or
AB (consumer* N2 directed) or AB (consumer* N2 run)
S28 s24 or s25 or s26 or s27
S14 and S27
S28 qualitative studies/
S29 ethnographic research/
S30 phenomenological research/
S31 grounded theory/
S32 exp qualitative validity
S33 purposive sample
S34 exp observational method/
S35 content analysis/ OR thematic analysis/ OR interpretative phenomenological analysis/
S36 constant comparative method/
S37 field studies/
S38 theoretical sample/
S39 focus groups
S40 phenomenology/ OR ethnography/ OR ethnological research/
S41 S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40
S42(qualitative or ethnon$ or phenomenol$).tw
S43 (grounded theor$ [or stud$ or research]).tw
S44 (case stud$.tw)
S45 (constant compar$).tw
S46 (purpos$ sampl$).tw
S47 (focus group$).tw
S48 (emic or etic or hermeneutic$ or heuristic or semiotics).tw
S49 (data satura$).tw
$50 (participant observ$).tw
S51 (Heidegger$ or colaizzi$ or spiegelberg$).tw
S52 (van manen$).tw
$53 (merleau ponty$).tw
S54 (husserl$ or Giorgi$).tw
$55 (lived experience$).tw
S56 (narrative analys$.)
S57 (life experience$ or experiential/) tw
S58 (exp cluster sample/)
S60 S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53
```

OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60

This search yielded an initial result of 1332 articles, which was reduced to 373 following application of the adult and English language limiters. This was then followed by a more iterative, hand-searching approach in which key articles identified in the first search were then used as the basis for finding other relevant studies (some of which had been identified successfully by the first search), along with the "bottom-up" approach of reference-searching key PS studies already known to the reviewer through her research network, an approach known as berry-picking (Finfgeld-Connett & Johnson, 2013). This part of the search yielded a further 69 articles. These articles were then title and abstract reviewed, resulting in a selection of 17 articles identified as appropriate for in-depth, full-article checking, and eight articles for final inclusion in the review.

As has been discussed previously (e.g., Wu, Aylward, Roberts & Evans, 2012, for a review of this issue), using a linear, top-down approach alone, is unlikely to result in a selection of articles relevant or sufficient for a reliable qualitative review of the literature. This is due to a range of problematic issues specific to searching qualitative research, related in part to the pluralism in qualitative methods which has been mirrored by a lack of standardised indexing of qualitative articles within databases. In addition, the term "qualitative" is broad, and the style of reporting within qualitative research so varied that locating relevant literature can pose a significant challenge (Grant, 2004). Further, a substantial amount of qualitative articles employ idiosyncratic titles (Evans, 2002), often based on direct quotes from participants, which although attractive can complicate retrieval. Another challenge, specific to this review, and reported here in detail for transparency, was in locating relatively rare service-user qualitative data within articles where the emphasis was on the professional perspective on PS; something which necessitated detailed checking of articles initially

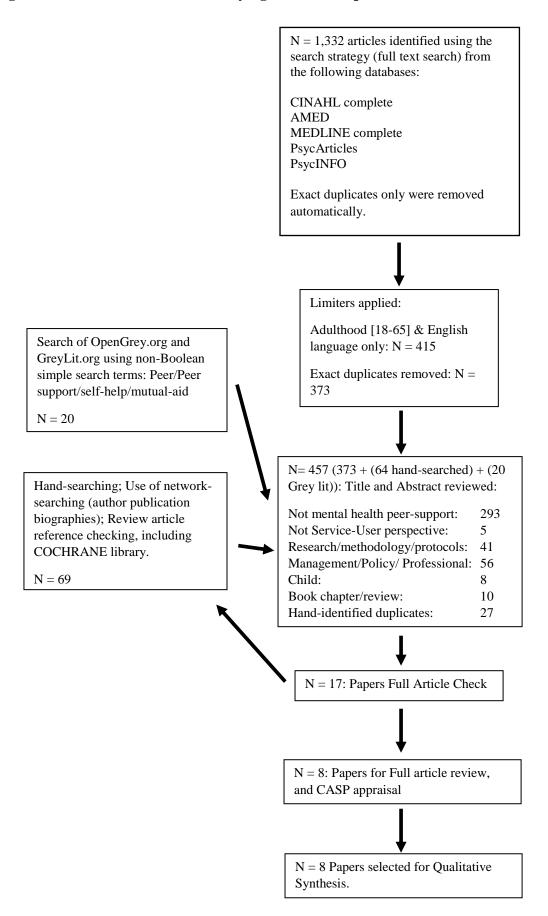
rejected. Finally, potentially valuable "nuggets" of service-user perspective data were located within mixed-methods papers and not overtly signposted within the articles themselves, and thus required additional hand-searching.

# **Quality appraisal**

Structured appraisal tools in their own right are no guarantee of reduced bias during paper selection (Dixon-Woods et al., 2007), but do form part of an audit trail that may be followed by others wishing to evaluate the work, and can provide a helpful framework for the reviewer's own thinking. For this review, studies were critically appraised for quality using the Critical Appraisal Skills Programme (CASP, 2016). The CASP tool provides a structured approach to appraising studies and comprises 10 questions; the first two screen out studies lacking any clear aim and/or where qualitative methodology is inappropriate, while the next eight focus on research design, recruitment strategy, data collection, researcher reflexivity, ethics, analysis and the implications of the findings, and value of the research. For each question, there are three possible responses; 'yes', 'no' and 'can't tell', although no numerical scoring is provided. Following supervisory discussion, a numerical scoring system was devised based on the three possible responses; a score of '2' for a good, clear response, for instance where authors explicitly described the data collection or analysis method or engaged transparently with issues of researcher reflexivity; '1' for a weaker response with fewer details, where for instance analytic methods were mentioned but not elaborated or justified; and finally a score of '0' for studies in which no information was provided for that question. Scores for all ten questions were totalled for each article, with a maximum possible score of 20 (Appendix A), enabling quality comparison of the papers to be carried out and for this information to be incorporated into the findings of the synthesis.

No articles were rejected solely on the basis of a low CASP score, due to the low numbers of articles identified from the search, but rather their relative merits were appraised critically using the CASP criteria, alongside the degree to which they represented the service user perspective of PS. The lack of literature including service-user perspectives is of central concern within PS research, and by choosing to undertake a review in this area, even if low-quality studies are included, this issue can be highlighted.

Figure 2: Search Process for Identifying Relevant Papers



#### **Data Extraction**

The selected articles were contextually and methodologically heterogeneous, and varied in their aims and conclusions; differing in the relative emphasis on evaluation or conceptualisation. In considering how best to extract the data from the selected articles, there were three main considerations; firstly that the review question be held in mind so that the emphasis on identifying service user perspectives would be retained as the priority; second that the contextual factors of each study could be systematically recorded and separately appraised using the CASP quality appraisal tool (CASP, 2016); and three by using a transparent and systematic process of extraction an "audit trail" would be provided from the initial articles through to the extraction and integration of the findings (Noyes & Lewin, 2011) to support plausibility of the final interpretative phase.

The term "data" was taken to mean any qualitative findings relating to service user experiences within the "results" or "findings" sections of each article. Both direct service user data in the form of quotes, and indirect service user data in the form of summaries of their experience was included, although the former was prioritised.

A first data extraction form was used to record contextual characteristics such as setting, type of PS, data collection and method of analysis, while a second data extraction form was used to record service user quotes and secondary interpretations referring to the service user perspective (Appendix B).

#### **Synthesis Method**

Given that the majority of PS interventions in the United Kingdom for mental health are delivered within mental health settings, complete homogeneity in the chosen studies would have arguably made it easier to synthesise findings across the studies. However, while the articles identified through the search strategy shared similar elements, inevitably there was variation in recruitment and sampling methods (when reported), and a range of peer-support settings. An approach based on narrative synthesis was used, which has previously been used in reviews where contributory studies are heterogeneous in method and context (e.g., Day, Jones, Languer, & Bluebond-Languer, 2016). In their critical review of methods for synthesis of qualitative research, Barnett-Page and Thomas (2009) discuss a range of approaches that can be distinguished to the extent that they attempt to aggregate existing knowledge or create new knowledge through reciprocal translation (Noblit & Hare, 1988) and by the extent to which they actively engage with heterogeneity between different studies. The level of interpretation versus simple description is a subjective decision based on the evidence available (amount, quality, range) and the aim of the review question (aggregative versus theory-building). Therefore, for this review, it was decided that in order to stay closer to the original data and service user perspective, predominating themes would be identified without an attempt to create a model of PS. Consequently, a method of synthesis was chosen part way between the simply aggregative and the more interpretative methods.

The synthesis comprised multiple stages. Firstly, the chosen articles were read and re-read repeatedly, key findings, emergent themes and notes of interest were recorded using the data extraction forms. Methodologically relevant factors were recorded where provided, including aims of the study, analytic methods used, researcher context, service setting and sample characteristics to contextualise the

contributing data, and to enable consideration of quality in determining the relative contribution of findings to the overall conclusions. Emergent themes were noted and grouped where related into over-arching themes. Finally, a narrative summary for each theme with supporting service user quotes was prepared as the final product of the synthesis.

#### Results

Following CASP appraisal, completion of both extraction forms was repeated for each article, and then a summary table of descriptive characteristics was created to summarise setting, methods and key findings (Table 1). A table of themes was generated to illustrate the strength of these themes based on their prevalence across the papers, and to highlight disagreement or difference (Table 2).

#### **Characteristics of Selected Studies**

Of the selected articles, four took place in the United States (Gidugu et al., 2015; Cabral, Strother, Muhr, Sefton, & Savageau, 2014; Davidson et al., 2001; Salyers et al., 2009), two in Australia (Lawn, Smith & Hunter, 2008; Henderson & Kemp, 2013), one in the United Kingdom (Gillard, Gibson, Holley, & Lucock, 2015) and one in Canada (Wrobleski, Walker, & Jarus-Hakak, 2015). The number of service user participants ranged from seven to 49, and only one study provided a detailed breakdown of age (Gidugu et al, 2015), with a reported mean of 47 years. Of the two studies reporting ethnicity (Gidugu et al, 2015, Henderson & Kemp, 2013), the majority of participants were white or Caucasian. Gender split was reported for 92 of the total 148 service user participants, with 59 female participants and 33 males.

The selected studies varied in terms of data collection methods, methods of analysis and the range and quality of service user data provided; six used semistructured or open-ended or interviews (Cabral et al., 2014; Davidson et al., 2001; Gidugu et al., 2015; Gillard et al., 2015; Salyers et al., 2009; Wrobleski et al., 2015), one used a focus group (Lawn et al., 2008) to gather data. Four studies used a thematic approach to analysis (Gidugu et al., 2015; Lawn et al., 2008; Henderson & Kemp, 2013; Salyers et al., 2009), one used content analysis (Wrobleski et al., 2015), one study used a consensus coding approach (Cabral et al., 2014), one used grounded theory (Gillard et al., 2015), and one a phenomenological approach (Davidson et al., 2001). The setting of the research studies also varied widely with several studies recruiting from multiple settings including statutory mental health services, voluntary and partnership agencies and peer-partnership where PSWs held management roles (see Table 1). No studies presented data from in-patient peersupport. All peer work was delivered individually, and the majority of PS work was reported as delivered by trained PSW who were also formally employed. One study used a manualised, peer-delivered intervention (Salyers et al., 2009).

#### **Synthesis**

**Emotional, social and practical support** (reconnecting; opening up new horizons; demonstrating commitment; doing normal things together)

Common to all of the selected studies bar one (Wrobleski et al., 2015) was the importance to service users of having different types of support available to them from their PSW. Service users valued the emotional support offered from having someone with them to combat isolation, but also valued the sense of acceptance that

came from associating with "normal' people doing 'normal' activities." (Davidson et al., 2001, p. 289), such as going out for coffee or accessing local amenities.

Having the emotional support of the PSW when accessing local amenities or reconnecting with former social groups was particularly valued because service users sometimes lacked the self-confidence to do this alone.

"...picks me up so that I get out of the house". (Henderson & Kemp, 2013, p. 154).

"...peer support workers...help give you the confidence to start doing the activities of daily living..." (Gillard et al., 2015, p. 440).

Practical support was highly valued for two reasons; firstly that service users appreciated having someone with them who 'knew the system', and could help them navigate more successfully than they might do alone, such as accompanying them to appointments, helping with shopping or facilitating access to social resources. Secondly, practical, instrumental support was, interestingly, seen by service users an important means by which they could witness their PSW's commitment to, and acceptance of them:

"I needed the tangible, and I needed the personal and emotional support, also. And, with her helping me with both of those situations, it took the stress off of me, where I could focus on other things that were important". (Gidugu et al., 2015, p. 448).

One participant describes the value to her of the reliability and commitment her PSW showed to her by returning repeatedly even when she, the service user did not feel well enough to engage:

"She never let me go...when I couldn't see her, she came to me. She never let me go...I've never had that many friends that were that faithful." (Davidson et al., 2001, p. 283).

It is possible that the practical support offered by PSWs is valued by service users because it provides a mean by which they can test and appraise their PSW and decide, at their own pace, if they feel safe enough to continue with the relationship. The overt demonstration of commitment through practical support, and going beyond the usual tasks offered by non-peer staff, could therefore act as a building block towards establishing the relationship.

The Centrality of Relationship (being on a level; credibility through sharing of lived experience; a sense of safety and genuineness)

Henderson and Kemp (2015) suggest that the benefits of receiving support may be variable and could be linked to 'culture', which they define as perceived similarity and perceived experience, including factor such as gender, age, and ethnicity. They suggest that the sharing of lived experience may mitigate cultural differences between pairs of service users and PSWs because it is valued over and above any cultural differences, thus bringing a sense of credibility to the PSW's interactions.

Lawn et al (2008) reported that service users felt more trusting of someone who knew from their own experience what symptoms of mental illness were like, and appreciated the less formal, non-medicalised approach used by PSWs. Feeling "safe" and having a sense of "comfort" with their PSW appeared to be closely linked with knowing that they shared similar experiences; this "levelling" enabled a

different type of conversation to occur, suggesting an authenticity to the interactions that may be harder to obtain in non-peer interactions:

"There is a mutual understanding. We are on [an] equal footing not like the psychiatrist where they are like an authoritative [sic] figure." (Cabral et al., 2014, p. 108).

"We're both on medication. We've both been in hospitals. So there was that kind of bonding too." (Davidson et al., 2001, p. 289).

"...and shared a little of her story with me. And, um...that was very comfortable. Um...it made it a lot more comfortable to share back. It makes it more...more personal. Not...so clinical." (Gidugu et al., 2015, p. 449).

Peer Support Worker as a bridge between Service Users and Mental Health teams (Illness as an asset; advocacy; challenging stigma; educating nonpeers; filling the gaps)

The third theme of service users appreciating the bridging role of PSWs between them and mental health professionals was presented in four studies, and the "gap" appeared to be both a literal and metaphorical in that some service users perceived a "gap of experience":

"I don't know the personal history of the staff...there's that sort of gap that staff have to have with service users...[peer workers], they've been through something themselves and are here and it's benefitted and they get on with the staff..." (Gillard et al., 2015, p. 440).

 Table 1. Descriptive characteristics of selected articles.

Author/ Year of publication/ Country	Sample	Setting/Type of Peer support	Method of data collection	Method of analysis	Quality score	Main Findings
1. Gidugu et al./2015/ United States.	19 Service users 12 female; mean age 47 years (35- 59) 47% white, 21% African-American 25% Hispanic 5% Native American	Large, not-for- profit.  Individual Peer- Support. Formal/employed.	Semi-structured interviews.	Not explicitly stated - appears consistent with thematic analysis.	14	Service users (SU) valued demonstration of reliability via practical help; gave a sense of peer support worker (PSW) "going beyond". For some SU role confusion and boundary issues were of concern. Sharing of lived experience (LE) key to successful relationship and restoration of humanity via core conditions of warmth, empathy and genuineness. Sharing of LE associated with SU reports of normalization and improved selfesteem.
2. Gillard et al./2015/United Kingdom	18 Service users No further info.	10 different settings: statutory; partnership; voluntary.  Not stated; variation assumed – although data suggest at least some were paid, formalized roles.	Inductive, open- ended interview; comparative case study.	Grounded Theory (Strauss & Corbin, 1998); Constant Comparison process (Green & Thorogood, 2004).	18	SU saw mental illness as asset for work due to PSW role; provided hope [of a contributing future], role-modeled recovery, and reduced [internalized] stigma. SU appreciated having a PSW to meet them at the mental health team as a bridge to health professionals from whom SU reported experiencing casual or inadvertent stigma; a barrier to engagement.

 Table 1. Descriptive characteristics (cont.).

Author/ Year of publication/ Country	Sample	Setting/Type of Peer support	Method of data collection	Method of analysis	Quality score	Main Findings
3. Cabral et al./2014/ United States	10 service users. 50% female. No further info.	Trained PSWs provided services in either a residential or supported independent living programme.	Face-to-face interview.	Consensus coding approach.	17	SU reported lived experience was most important to the SU-PSW relationship. PSWs were more concerned with role ambiguity and boundaries than the SU. SU appreciated the unique role of PSWs within the team and that they could educate others about recovery.
4. Wrobleski et al./ 2015/Canada.	9 service users. No further info.	Statutory. Peer partnership agency. Trained, employed. Individual peer support; 2 hrs per week for 6 months.	Semi-structured exit interview.	Content analysis (Hsieh & Shannon, 2005).	20	Developing a therapeutic alliance and managing interpersonal boundaries were most important to SU. Some SU did not realize they would hear PSWs story of lived experience. Similar outcomes for peer and non-peer conditions.
5. Lawn et al./2008/ Australia.	49 service users. 75% female. 25% of total in 18-25 year old age bracket. (pilot study) No further info	Trained, employed. Individual peer support. "Packages of peer support" focusing on instrumental and emotional support: 8-12 hours over a 1-2 week period. Statutory, mental health service.	Phone questionnaires and focus groups.	Informed by thematic analysis.	13	SU felt PSWs had credibility & trust them due to lived experience; valued their use of non-medicalized language. SU could discuss things with a PSW they wouldn't feel comfortable talking about with a health professional. Meeting someone who had been unwell and who was doing well was normalizing; improved self-understanding (reduced self-stigma), self-belief (empowerment) and belief in the potential for recovery (hope). Role-modelling for recovery.

 Table 1. Descriptive characteristics (cont.).

Author/ Year of publication/ Country	Sample	Setting/Type of Peer support	Method of data collection	Method of analysis	Quality score	y Main Findings
6. Henderson & Kemp/2013/Australia.	9 service users. 100% male. One indigenous Australian One Micronesian Seven Caucasian. No further info.	Formalized. Delivered within "mental health agencies" and focused on "healthy lifestyle behaviors".	Nominal group technique (Delbecq et al., 1975). SU's prioritized and ranked responses.	Informed by thematic analysis.	16	PSW motivated by safe challenging in a safe way and by encouragement. Practical support facilitated social engagement and increased awareness of social networks and community activities. Positive mental attitude, confidence improved selfmanagement skills.
7. Davidson et al./ 2001/United States	7 service users. Living in the community. No further info.	Community-based programme.  Voluntary; Individual peer support.	Semi-structured interviews and focus groups.	Phenomenological (Giorgi, 1970. Wertz, 1983).	17	Demonstration of acceptance and commitment; valued consistency and regularity in contact. LE aided acceptance and a sense of welcome. SU valued: transition role of PSW to 'normal friendship(s)'; easing of perceived social pressure via normalization. Felt less stigmatized due to LE. Non-mental health bonding also valued. Role modelling.
8. Salyers et al./ 2009/United States.	11 service users. 'Just under half' female.	1 PSW, formalized, trained, paid. Manualized – illness management recovery at SU home.	Semi-structured interviews.	Informed by thematic analysis.	10	SU valued lived experience and the PSW role model; inspirational and enabled them to imagine a brighter future for themselves. Seeing that someone with a mental illness could use this experience to get a job gave hope.

**Table 2:** Table of themes.

First Author/Year	Emotional, Social & Practical support Demonstrating commitment Doing normal things together Reconnecting Opening up new horizons	The Centrality of Relationship Show me I can trust you – consistency; reliability; commitment. Being on a level Credibility through sharing of lived experience A sense of safety and genuineness	PSW as a bridge between SU and MH teams Illness as an asset Advocacy Challenging stigma, Educating non-peers. Filling the gaps	Role-modelling recovery Normalising through sharing lived experience Hope & Inspiration Imagining alternative futures	Managing boundaries The balancing act Relationship anxiety Expectations and Communication	Self-efficacy and taking charge of recovery Handing over the reins Moving away from illness identity	Mutuality and contribution. Wanting to offer support and friendship to the PSW. Re-connecting through contribution
Gidugu et al. (2015)	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	×	<b>√</b>
Gillard et al. (2015)	<b>√</b>	<b>✓</b>	<b>√</b>	<b>✓</b>	×	<b>√</b>	×
Cabral et al.(2014)	<b>√</b>	<b>✓</b>	<b>√</b>	<b>√</b>	×	×	<b>√</b>
Wrobleski et al. (2015)	×	<b>√</b>	×	×	<b>~</b>	×	×
Lawn et al (2008)	<b>√</b>	<b>✓</b>	<b>√</b>	<b>✓</b>	*	×	×
Henderson & Kemp (2013)	<b>√</b>	<b>✓</b>	×	×	×	<b>√</b>	×
Davidson et al. (2001)	<b>✓</b>	<b>✓</b>	×	<b>✓</b>	×	<b>√</b>	<b>√</b>
Salyers et al. (2009)	<b>√</b>	<b>√</b>	×	<b>√</b>	×	<b>√</b>	×

While others perceived a "consistency gap" and valued their PSW chasing up case managers or other health professionals who were seen as too busy to be reliable:

"...I got some backup, because this guy [Case Manager] wasn't doing nothing...she helped me do that, fixed it." (Gidugu et al., 2015, p. 448).

This links in with the first theme of demonstrating trust through instrumental support, and suggests that that the advocacy role performed by some PSWs may have been of value to service users who had not received such "good service" from mental health professionals prior to working with their PSW.

Some service users expected to experience casual or inadvertent stigma from mental health teams, and some were reluctant to engage because of this and the related sense of not being on a level with their health professional:

"...It means the moment you come through the door you know you've got somebody that's going to treat you well because they've been there themselves... and there isn't that stigma you sometimes get as well." (Gillard et al, 2015, p. 440).

The PSW was able to mitigate this relationship anxiety for the service user, and was

perceived by service users as being able to challenge stigma (both external and internalised) through educating mental health professionals in non-peer roles that people with mental illness can be in recovery and work (Cabral et al, 2014).

Moreover, their mental illness was actively an asset and seeing them employed gave service users a sense of hope that they too might be able to do something similar with their lived experience:

"...the essence is the amount of hope that it gives to other service users, that from...having this label of service user, you might one day be able to be a service

user worker...they were actually able to be part of an organisation...a very useful and important service..." (Gillard et al, 2015, p. 440).

**Role-modelling recovery** (normalising through sharing lived experience; hope and inspiration; imagining alternative futures)

Salyer's (2009) study detailed how the majority of service users valued the optimism of their PSW and the encouragement they provided. Seeing that they had obtained employment gave them hope and motivation especially if they had limited positive examples of others living well with mental illness, and spoke to a need for social connection that was not diminished by symptoms of mental illness:

"...before I met him, um...there was only one person that I've ever known that had...mental illness" (p. 199)

Service users in Gidugu et al.'s (2015) study commented that seeing that their PSW had "done it" gave them hope through a process of normalisation aided by their PSW sharing their lived experience. For service users this was valued because it meant others felt like them but could still live well:

"...them just talking about their experiences was more of a help than I can think a lot of...than they could imagine."; and "She did it....if she can do it, I can do it, you know?" (p. 449).

This role-modelling function was evidenced in six studies and it was important to service users that their PSWs were further ahead in their recovery because they could in a sense, see for themselves what might be possible for them, further down the road, and that being in recovery was an on-going process:

"It buoys you up as well because you know that these people are able to get on with their lives...and they've managed to do that even through mental health issues..." (Gillard et al., 2015, p. 439)

"She helps me move on to my next stage of recovery. I see her as a person who has reached her goals, but is also human, and things came crashing down on her, but she was able to move on. She is a good role model." (Cabral et al., 2014, p. 108).

**Managing boundaries** (the balancing act; relationship anxiety; expectations and communication).

Only two of the selected articles presented boundary issues as a theme of concern to service users (Gidugu et al., 2015, Wrobleski et al., 2015). In Gidugu et al., (2015) some service users reported a lack of clarity about the scope of the role, including the centrality of lived experience. This suggested a lack of knowledge about the role and a poor appreciation of the importance of clear communication and the clarification of expectations for service users:

"I didn't really know what kind of program I was going into when I got there. Yeah, I had no idea what that was." (p. 447).

Such concerns were not universal in the Gidugu et al., (2015) study because there was wide variation in perceptions of the scope of the role; some service users knew about the role because they knew other service users who had been in a peer support program, or because they assumed that the role would be similar to previous mental health support type roles they had benefitted from previously. There appeared to be little explicit awareness of the centrality of lived experience

to the peer role, suggesting poor communication and knowledge within the mental health team about the peer role:

"Could you please, somebody, give me a job description of what my peer support person *can* and *cannot* do." (p. 447).

Wrobleski et al.'s (2015) study reported service user discomfort on hearing the stories of lived experience of their PSWs with one service user reportedly feeling "overwhelmed" (p.69), hinting at the relatively high levels of communicative skill required for the role, and the importance of timing disclosure carefully to ascertain if to do so would be helpful for the service user.

Unfortunately, some service users in this study felt they were "providing support in the match rather than the other way round" (p.69).

However, some service users in Gidugu et al.'s (2015) study valued their PSW doing more than might usually be expected because of the feeling of emotional support this engendered. This finding also related to the first theme in which some service users valued concrete demonstration of commitment and acceptance from their PSW to build trust and aid the development of the relationship.

**Self-efficacy and taking charge of recovery** (handing over the reins; moving away from illness identities)

In four of the selected articles there was evidence from service users themselves that peer support was helpful in promoting a sense of responsibility for their own recovery. This effect appeared later on after the direct peer support which was reported as a facilitating influence on social re-connection and engagement with meaningful activity.

The importance of being introduced to activities was common to the selected articles as a means to building confidence and motivation prior to taking on activity independently:

"...peer worker motivates me to do things for myself"; and "builds confidence as a result of doing something." (Henderson & Kemp, 2013, p. 155).

Service users in Davidson et al.'s (2001) study described this supported socialisation as a kind of "jump start" (p. 281), which over time gathered momentum and for one service user felt like the "best antidepressant" he could have taken (p.281). This theme linked to the role-modelling effect of witnessing another person living well with their illness, thus challenging internalised preconceptions about what was achievable for themselves:

"My partner is mentally ill...to an extent he's fairly you know, with it." (p. 290)

While another service user in this study reported that having a PSW had taught her that she was capable of forming friendships despite her illness:

"I can develop a friend being mentally ill. I found that out. I don't know how yet, but I know I can" (p.290).

One service user in Gillard et al.'s (2015) study described the gradual process of their PSW stepping back (along with other sources of support) as their confidence and independence grew and the value of their continued, albeit less hands-on support:

"...peer support workers can be the people that help give you the confidence to start doing the activities of daily living...people naturally start backing off from

you because they have to, to let you take more control...I think it's then that the peer support worker would really be able to help, to say "I understand where you're at. I felt so overwhelmed and this is how I dealt with it".

This role of the PSW as facilitating the transition towards increased self-efficacy was likened to a "coaching role" by Henderson & Kemp in their 2013 study (p. 154) where encouragement combined with challenge was provided. They argued that this type of support was accepted by service users because of the quality of trust developed earlier in the relationship, something mediated by the sharing of lived experience (first from the PSW, and then reciprocally).

**Mutuality and contribution** (wanting to offer support and friendship to the PSW; re-connecting through contribution)

As the relationship with their PSW developed, the findings of the studies suggest that service users began to make comparisons between themselves and their peer support, in some cases possibly realising that there were fewer differences than they had first imagined:

"...he drives and I don't, and that he does certain things that I don't, but I do certain things that he doesn't." (Davidson et al., 2001, p. 289).

This kind of positive yet realistic comparison suggested a growing sense of esteem in the self, coupled with a realisation that they wanted to give something back:

"We just talk, and just share our support. Share our support. I like to think I'm giving some, too, back." (Gidugu et al., 2015, p. 449).

While only Gidugu et al., (2015) and Davidson et al., (2001) directly reported mutuality in the relationship, it is possible that PSW/service user mutuality

generalises to a desire to contribute more broadly through, for instance, community involvement, training to become a PSW (Cabral et al., 2014) and engagement in meaningful activity with others.

#### **Discussion**

For simplicity, the themes are presented in descending order of representation across the chosen articles, but this is not intended to imply a hierarchy of importance.

# The Centrality of Relationship

All eight articles contributed to this theme, and findings were predominantly experiential, suggesting that service users valued quality of relationship. Participants felt safe and trusted their PSW, and described the experience as more credible, authentic and equal to non-peer relationships because of PSW disclosure.

The importance of equality and safety in relationship as a basis from which recovery can begin has previously been described by Repper and Perkins (2003) in their model of social recovery. They argued that attention should be paid to issues of power, vulnerability, exposure, dignity and respect, because of their ability to promote or undermine recovery. Paulson et al., (1999) described how service users, when interviewed about their experiences of working with peer providers, were more likely to emphasise the experiential nature of the relationship (the "being") compared with non-peer helping relationships (the "doing"), and therefore the importance of relationship to service users receiving PS has precedent.

Mead et al., (2001) have argued that equality in helping relationships provides a means for personal growth and mutual support, which may be less

achievable where unequal power dynamics undermine the taking up of a more active role in recovery, something associated with better outcomes (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Moving away from hierarchical power structures in the PS has previously been suggested as one way in which the PS relationship may facilitate recovery (Mead & MacNeil, 2006), and the current findings suggest that a sense of parity is associated with a feeling of comfort or safety, which may in turn support the development of the PS relationship.

# **Emotional, Social and Practical support**

Seven articles contributed to this theme. Practical, instrumental support was valued by service users as much as the emotional and social support it appeared to precede. This suggests that in addition to credibility through lived experience, perceived usefulness and competence were also valued by service users. Service users appreciated assistance with practical tasks of daily living, because it freed them up to engage more actively with recovery, and because it provided concrete demonstration of commitment and acceptance, which in turn supported the development of the PS relationship.

Understanding mental health difficulties in ways that incorporate social as well as intra-personal factors is accepted, and therefore models of PS need to give sufficient recognition to the notion that some service users may value practical help overcoming such barriers to engagement. Therefore some element of dependency may be unavoidable especially in the earlier stages of the relationship, and need not be viewed negatively. Indeed, Leamy et al., (2011) mapped change models of recovery to a trans-diagnostic model of change (Prokchaska & DiClemente, 1982) and suggested that a state of 'aware dependency' (p. 449)

precedes inter-dependency and independence, mirroring the progression from contemplative to action stages. It has also been previously argued that models of recovery that emphasise individualistic notions of empowerment and independence (Davidson, Harding, & Spaniol, 2005; Slade, 2009) and models of PS that similarly emphasise control and opportunity (Repper, Aldridge, Gilfoyle, Gillard, Perkins, & Rennison, 2013) may simultaneously maintain individualistic models of mental illness, and may not account for recovery in more collectivist cultures, where healthy inter-dependence is the norm (Leamy et al., 2011). Repper and Carter (2011) argue for a model of PS consistent with these findings, comprising (amongst other elements) shared meaningful activity within a collaborative relationship. It is possible that the findings of this review support an extension of this idea, in which the meaningful activity may be more or less shared according to the individual nature of the relationship, and the relative stage of service user recovery.

#### **Role-modelling Recovery**

Six of the eight selected studies provided evidence to support the notion that PSWs are role-models to service users. Service users valued their PSWs as a living example of living well with mental illness, which was experienced as normalising and gave them hope and motivation for their own future. The instilling of hope and motivation for one's own recovery by PS, is consistent with existing models of PS, in which hope, meaningful activity, self-efficacy and self-management are key (Repper & Perkins, 2003; Shepherd et al, 2008). Theoretically, it is also consistent with Festinger's (1954) Social Comparison Theory, in which he describes how as humans we make use of information for 'self-improvement' (Wood, 1989) gleaned from others perceived as similar to us who are further along towards a common goal

(such as recovery in mental health). By working with a PSW who they perceive as both sufficiently similar and at the same time sufficiently ahead in their recovery compared to them, the combination of perceived similarity through shared experiences on the one hand combined with outwardly observable signs of recovery and living well with mental illness on the other, together form one potential mechanism for change in successful PS.

The finding that service users recognise their PSW as role-models is also consistent with existing explanatory models of peer support (Davidson et al., 2012), although the current findings suggested that role-modelling may work by facilitating a kind of imagined recovery, prior to its implementation, and may again map on to models of change in which motivation through inspiration can help individuals progress towards action. This finding parallels the well-known process of role-modelling generating hope in peer support and recovery41, but the novel emphasis on the service-user perspective has highlighted a possible way for this process to be identified as an outcome of successful peer support, although more research is clearly needed.

# PSW as a bridge between MH teams and SU

Half of the studies presented evidence to suggest that PSW may act as ambassadors or advocates for service users to mental health teams, and findings suggested that PSWs could help challenge internalised stigmatising beliefs.

Again, this finding suggests that models of PS need to incorporate a recognition of the barriers to engagement and recovery that are both intra-personal and social in origin, and that PSW may act to improve engagement and eventually social functioning because they can span both perspectives, mediate and share

knowledge. This would suggests that the PS relationship offers a space within which learning can occur through the sharing of knowledge, observation, and practice, an interpretation consistent with Mead et al's (2001) notion that the relationship provides a safe space within which new wellness identities can be practised.

Models of recovery that posit improved social functioning (Davidson, 2003) and connectedness (Leamy et al., 2011) as key outcomes, may be understood as complementary to models of PS that link such outcomes with the earlier acquisition of "street smarts" (Davidson et al., 2012) via the sharing of experience and modelling. The findings in this theme suggest that the advocacy role is valued and may have the added benefit of supporting engagement, although this requires further empirical support.

# **Self-efficacy and Taking Charge of Recovery**

Half of the selected articles contributed evidence to this theme. Service users suggested that challenge is welcome where there has been sufficient time to allow the PS relationship to establish.

The importance of temporality in any PS model is important to recognise because the rate of recovery may vary relative to the degree of self-efficacy and reciprocal engagement with mental health teams, amongst other factors. Such an interpretation suggests that PS programmes should be supported to work flexibly with individuals in terms of length of intervention, and that models of PS may benefit from incorporating a sense of temporal progression, and an understanding of the individual nature of recovery (Leamy et al., 2011). Consequently, future service evaluations of PS will also need to consider where participants are along their

recovery journey, and ensure that the use of outcome measures accounts for such variability.

## **Mutuality and Contribution**

While only three articles directly mentioned mutuality or reciprocal support, it is possible again that mutuality is an element of PS that requires other elements to be firmly established first, such as confidence and trust in the relationship. In the context of the other findings from this review, mutuality may potentially be linked conceptually as one outcome of successful role modelling, where such modelling leads to the processes of hope and imagined brighter futures as presented earlier.

Indeed, the studies that evidenced mutuality as a theme, (Gidugu et al., 2015; Cabral et al., 2014; and Davidson et al., 2001) researched peer support schemes that were well-established. Therefore they may have provided sufficient time for at least some service users to experience mutuality within the relationship. Longitudinal studies focusing on service user perceptions of mutuality, as a developmental stage and/or outcome of successful processes within the PS relationship, could be a useful and interesting addition to current understanding.

## **Managing Boundaries**

Finally, just two of the selected articles discussed issues relating to boundary concern, and represented a rare example of evidence of negative service user experience in PS in these studies. These negative experiences surfaced due to what appeared to be poor communication about what the PS role was and was not, rather than any over-stepping of boundary. Repper & Carter (2011) suggest that boundary management may also be of concern to organisations in implementing PS within organisations, although the provision of educational programmes about

PS to both peer and non-peer staff is best practice (Davidson et al., 2012), and guides are currently available for this purpose (Challis, 2016). While other studies have argued that without a degree of flexibility and individualisation to boundary setting, it may be more difficult for PS relationships to develop reciprocity and mutuality (Mead et al., 2001). Clearly there is a balance that needs to be struck to maintain appropriate flexibility and role creativity within a framework that supports ethical practice. Indeed, if improved social functioning is one outcome of successful PS and recovery, then behaviours associated with therapeutic boundary flexibility, such as meeting in informal settings (Solomon, 2004), and the use of a non-medicalised language (Mead & MacNeil, 2006), and judicious self-disclosure (Wrobleski et al., 2015), that may support earlier socialisation within the PS dyad, may well need recognising as a core element of what makes PS therapeutic and unique as an intervention.

# **Robustness of the Synthesis**

Strengths. A strength of this review is the inclusion of and focus on qualitative research, especially where such data was embedded in larger (mixed-methods) studies and was at risk of being overlooked. The review also provided an up-to-date review of the literature, including six papers out of a total of eight published since 2010; and in line with the review question focussed on recipient-perspective data, including the use of first-person spoken word data wherever possible. The review successfully identified seven themes representing active ingredients of PS from the perspective of recipients, thus prioritising what matters to recipients rather than providers of PS services.

In addition, the review has given over significant discussion to issues of methodology because these are seen as integral to context. The review has aimed for a balance between aggregative and interpretative elements in bringing together current understandings of service user experiences of peer support, while interpreting this in the context of existing theory. This approach has resulted in the production of a synthesis that is open to appraisal because it has embraced the subjective and contextual nature of both the contributing research and the process of review and synthesis itself.

Finally, the foregrounding of service user experience has brought some balance to current understanding of peer support and underlined the importance of developing both theoretical conceptualisations and outcome measures that reflect both the service user experience and what matters to them and what is helpful.

Limitations. Information about sampling, recruitment procedures and participant samples was sometimes limited in the chosen articles, and therefore there is a limit to which these can be reported in this review. Information was also limited in relation to diagnoses and presenting problems, presumably for reasons of anonymity, with most papers providing minimal information such as "a full array of disorders" (Lawn et al., 2008) or "range of affective and personality disorders" (Davidson et al., 2001), meaning that it is not possible to say for whom PS works on the basis of disorder, and therefore if 'diagnosis' is relevant to our ability to say on what basis and for whom PS 'works'". No papers explicitly engaged with issues of researcher reflexivity beyond acknowledgment of when a researcher was also employed within the peer service involved or had experience as a peer, and where this was the case, a "consensus oversight" approach was taken by using group supervision with non-peer researchers (e.g., Gidugu et al., 2015), although the extent

to which this would have been successful is impossible to know given that this is not reported. Clearly, more transparent reporting of researcher backgrounds is one way in which peer support research could address concerns of positive bias. My own position in interpreting the findings is also of relevance as a Trainee Clinical Psychologist within the NHS with experience of working in adult mental health. However, I have no prior experience or interest in peer-support prior to undertaking this review, and I have engaged in supervisory discussion throughout the development of this review to help me remain alert to the potential for bias in my own interpretations. To support transparency in relation to potential bias, a concerted attempt has been made to provide the reader with descriptive characteristics of each contributing article, where provided, including geographical location, sample description, setting, type of PS provided, method of data collection, analysis and main findings (Table 1) in summary form to facilitate the reader's own independent appraisal. Nonetheless, a limitation of the synthesis approach in general is that the assumptions and methodological limitations, where they exist, may be carried forward into the review itself. In further recognition of this limitation, data extraction tables are also included (Appendix B) in an attempt to contextualise the conclusions by making more explicit the strengths and limitations of the contributing studies. While articles with higher CASP scores and more service-user quotes (Gillard et al., 2015; Gidugu et al., 2015; Davidson et al., 2001) contributed proportionately more to the conclusions of this review (in terms of the number of times these studies were referenced) than those with good CASP scores but relatively fewer service-user quotes (Wrobleski et al., 2015; Henderson & Kemp, 2013; Cabral et al., 2014) and more still than the articles with the lowest CASP scores and fewest service-user quotes (Lawn et al., 2008; Salyers et al., 2009). However, there

were still methodological issues with the most frequently quoted article (Gidugu et al., 2015) in that their study included a variety of settings and did not provide participant demographic information, which it could be argued therefore impacts on the generalisability of this review. Conversely, supporting data was drawn from all the contributing articles, notwithstanding the "weighting" in favour of the "better" quality ones, and it is hoped that this, in combination with the inclusion of contextual information has resulted, overall, in a set of plausible conclusions that are located firmly within the contributing data.

A further potential limitation was the relatively high degree of overlap and agreement in what was identified as important to service users across the selected articles (although there were some inconsistencies in the detail around boundary issues, which as discussed, may have reflected how established the PS programmes under investigation were). More importantly, there were very few negative findings across the articles suggesting that sampling and recruitment may be problematic with this population, and that future studies should take care to report researcher characteristics in relation both to the study design and PS, and consideration should be given in future research how to implement designs that facilitate the reporting of negative experience.

Another limitation is that four of the eight selected articles were from the USA, or Canada; one was from Australia and two were from the UK (although the second-most quoted article in the synthesis was a UK-based study (Gillard et al., 2015). Local variations in practice and cultural variations in, for instance, the pace at which relationships usually develop or the language used to talk about experience may make direct comparisons problematic. In addition, there was no research available on the impact of multiple prejudices on PS relationship development, such

as ethnicity, sexuality or gender. It has been argued that recovery should be personally defined (Le Boutillier et al., 2011), and therefore awareness of the impact of issues of difference on the PS relationship needs attention. There is therefore a need for more service user perspective research in the United Kingdom so that recommendations for policy and clinical practice are relevant to local practice. Furthermore, there was only one article mentioning gender as a factor to consider in peer relationships, and while ethnicity was reported in two studies, no studies investigated the cultural effects of giving and receiving peer support between different ethnicities; this may be a useful avenue for future research, especially where services operate in culturally diverse settings.

Finally, it was unclear to what extent the reported findings in the studies were active or retrospective and therefore accounts reported closer to their initial occurrence may differ in quality to those reported more distantly.

#### Conclusion

A novel synthesis and narrative review of service user experience of PS has been presented. The findings support a model of PS in which temporal issues relating to the development of the PS relationship and of personal recovery are incorporated, so that desired outcomes such as increased self-efficacy may be understood to emerge later on in the PS intervention as a function of earlier processes of supported socialisation. Similarly, the personalised nature of each PS relationship suggests not only that implementation of organisational frameworks for PS should be flexible, but that PS training and supervision allows for adequate reflection to develop PSW self-awareness of personal boundary issues, and the value of flexibility. Education about PS to non-peer, referring staff and recipients

prior to enrolment is suggested, and supported by the findings of the review as a means to support informed consent and the individual's right to choose treatment.

Future research has been suggested including longitudinal studies that can explore the time-course of PS outcomes. More studies specifically focussed on service user perspectives would also be welcome to determine to what extent findings from this perspective map on to organisational and PSW priorities. Such priorities are likely to vary with contextual factors, including local population demographics and local service structures. Therefore, research designs that consider context and individual experience would complement larger-scale controlled studies and provide a useful means of testing emergent models.

## **Declaration of conflicting interests**

The Author declares that there is no conflict of interest.

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# **Bridging Section**

The empirical study presented aims to address the lack of any UK-based qualitative study of PS focussing *solely* on recipient experiences, as identified by the systematic narrative review. The articles within the systematic review were mostly non-UK-based, with recipient data embedded within larger studies prioritising the organisational and PSW experiences of PS delivery and implementation, thus inevitably limiting the attention paid to discussing the recipient experience. In addition, because of the analysis methods used, the level of interpretation was arguably insufficiently idiographic in its focus, resulting in a relatively superficial sense of what PS is like, how it is experienced and made sense of, and what matters to those who receive it.

The study also provides an important opportunity to support the development of how PS is conceptualised by providing a check to developing models of PS which in their early stages, have arguably not sufficiently considered the recipient perspective. In addition, it is hoped that it will contribute to refining implementation of PS programmes by determining what the helpful and unhelpful components are of PS, and to ensure that future models reflect all perspectives, and take into account local context.

# Service User Experiences of Mental Health Peer Support: An Interpretative Phenomenological Analysis

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Service User Experiences of Mental Health Peer Support: An

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Peer support; lived experience; experiential; phenomenological; service user

experience; mental health and illness; recovery.

63

#### **Abstract**

Peer support (PS) for individuals experiencing mental health difficulties is increasingly popular within mental health services, but studies are scarce that focus solely on service user experience. This study describes PS delivered by employed Peer Support Workers (PSW), and explores recipient experiences and sense-making. Five participants were recruited from an adult community mental health team in the United Kingdom. Data was collected by in-depth, semi-structured interviews, and verbatim transcripts were analysed for themes using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). Three super-ordinate themes were identified; the Power of Relationship, a Focus on Change, and the Psychological Impact of Peer Support. The presence of PSW's lived experience was felt to be critical. A period of reflection on identity and relationship preceded a period of more active change. The findings support the centrality of relationship over "intervention", and suggest that future peer support evaluations incorporate service user experience.

149 words.

#### Introduction

Since 2001, United Kingdom (UK) government policy has prioritised recovery-focused models of care in mental health with policies emphasising the importance of occupation, stable housing and social inclusion (Department of Health, 2001; Department of Health 2009, Department of Health, 2012). The employment of former service users as peer support workers (PSW) is a core part of this strategy and is supported by an implementation programme that seeks to identify and develop new roles within mental health services for those with experiential knowledge (Borkman, 1976) or "lived experience" of mental health, such as PSWs and course facilitators in Recovery Colleges (ImRoc, 2013).

Peer support (PS) can take various forms including self-help groups (Hardiman & Segal, 2003; Kennedy & Humphreys, 1994), clubhouses (Macias, Jackson, Schroeder, & Wang, 1999), and casual support (Davidson, Chinman, Sells & Rowe, 2006), and in terms of what is delivered as an intervention, can vary from emotional and practical support to manualised interventions based on cognitive behavioural therapy (CBT) principles, and can be delivered on an individual or group basis. PS can also vary in terms of setting, with some forms of PS delivered within statutory mental health services, while other PS programmes operate within voluntary or partnership organisations. This paper will focus on the type of PS currently being introduced and developed within the National Health Service (NHS) in the UK, where paid, trained PSW are increasingly formally employed within Adult Community Mental Health Teams (CMHT) to deliver face-to-face, recovery-oriented interventions, individually, to people with mental health difficulties.

Peer support in mental health has been well-described in previous research (see Repper and Carter (2011) for a useful overview), and is based on the principle that those who have experienced mental illness and found a way through it are well-placed to provide support, advice and encouragement to others experiencing mental health difficulties and who have further to go in their recovery. Mead, Hilton and Curtis (2001) describe the importance in PS of "empathic understanding through shared experience", and argues that it should ideally be founded on "mutual respect, shared responsibility and a shared agreement of what will be helpful" to both parties (p. 135).

However, while such definitions are appealing in their simplicity, evaluation of PS has been less straightforward with mixed or inconclusive results (Lloyd-Evans, et al., 2014) possibly suggesting an underlying complexity, as has been indicated in studies of other psychosocial interventions (Ruggeri, et al., 2012), along with a need to develop clearer mechanistic models of PS prior to conducting more meaningful evaluations (Solomon, 2004). Indeed, models to this point have tended to be hypothetical and theoretical, rather than empirically based. The development of a coherent model of PS that could be implemented and empirically tested could lead to further refinements of the model and also guide the training and supervision of PSWs.

Such models of PS have begun to emerge recently, such as Gillard, Gibson, Holley & Lucock's (2015), which was presented as part of a qualitative study, and placed building trusting relationships based on lived experience as the primary underpinning mechanism for the effectiveness of PS. The model was however partly speculative and was also based on findings from a diverse range of peer support

programmes potentially reducing its validity. The authors themselves called for more research to clarify the role of lived experience in a less varied range of settings acknowledging the importance of making sense of peer support as a contextualised psycho-social intervention.

While mechanistic models of PS may be currently under-developed, it is accepted that PS requires, by definition, lived experience. However, it is unclear how lived experience is shared, experienced and used by peer support workers, and therefore its mechanism of impact on recovery requires further clarification. Indeed disclosure within the context of the peer support relationship may be qualitatively different to that which occurs within non-peer therapeutic relationships (Henretty, Currier, Berman, & Levitt, 2014); this is currently not well understood. One possibility is that sharing in the lived experience of a PSW challenges internalised negative or self-stigmatising beliefs for service users, as identified in a recent paper examining the link between use of mutual help programmes and quality of life measures (Corrigan, Sokol, & Rüsch, 2013). Equally, demonstrating that recovery is possible could lead to a sense of optimism and a belief that the individual can make changes to create an alternative future. Indeed, Repper and Perkins (2003) suggest "hope, control/agency and opportunity" as three possible tenets of recovery.

While theoretical understanding of peer support is progressing, along with a growing acceptance that individuals with experience of mental health difficulties can contribute positively to improving mental health services, the perspective of service users who receive PS is under-represented in the literature. Moreover, current models of PS that are based on organisational or PSW experience alone, risk overlooking what matters to service users themselves. There is no published

research on individual peer support, in the UK, that has been designed to focus solely on how service users have received and experienced the intervention. Such studies are essential in supporting the development of PS both theoretically, but also in refining implementation by working out what the helpful and unhelpful components are, and to ensure that models reflect all perspectives, and consider local context. Finally, it is essential that all stakeholder viewpoints are represented because such views have a wider impact on the development and organisation of services.

Another important issue effecting PS is that in the United Kingdom, CMHT have, over recent years, had to operate under increasing financial constraint, and as a result, there has been a risk that PS programmes become seen as the "cheap option" (Vestal, 2013). Demonstrating effectiveness, irrespective of cost, has therefore been growing in importance. However, as has been argued, rushing to evaluate before there is sufficient theoretical understanding risks being counter-productive to the ongoing positive development of PS. While research is on-going to develop such models from which more meaningful evaluations can be designed, it is vital that all stakeholders are represented because what is seen as successful to one may not necessarily reflect the experience of the other.

Therefore, the research question for the present study, which examined PS provided by trained, employed PSW within UK-based CMHTs, asked, "How do service users experience and make sense of working with a Peer Support Worker?". Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) has been selected as the most appropriate method of analysis because of its dual focus on individual experience and wider theoretical interpretation, which

makes it ideal for research aiming to contribute to the development of models of PS that incorporate service user experience.

#### Method

# Design

A qualitative, idiographic approach was used with a small, purposive sample relatively homogenous in terms of age, location, and gender. Semi-structured, audio-recorded interviews were conducted to generate rich, detailed accounts, and transcripts were analysed using IPA (Smith et al., 2009).

All procedures contributing to this study complied with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration (World Medical Association, 2013). NHS ethical approval, local NHS R&D approval and Host University (University of East Anglia, UK) approval was sought and obtained (IRAS study reference number: East Midlands Research Ethics Committee: Ref: 16/EM/0109).

## **Materials**

A semi-structured interview schedule was developed with the intention of eliciting detailed responses from participants about their experiences. Questions were open-ended and facilitated the movement from description to interpretation of experience, to more reflective responses (e.g., "What were you first impressions of your PSW?" to 'How did hearing their story of lived experience impact on you?'). The schedule functioned as a guide only; and interviews followed the personal interests of the participants. Schedule development was discussed and reviewed at the study proposal stage by internal review at the host institution, and by a service-

user panel within the host NHS Trust, and was subsequently amended for content and clarity. A copy of the schedule is included in the Appendix (Appendix C).

# **Participants**

Five service users, four female, one male, were interviewed (four at home, one at clinic) and were selected based on the following pre-specified inclusion criteria:

- Have received a minimum of six hours of individual, face-to-face PS, within the past 12 months;
- Be at least 18 years old;
- Be well enough to participate, as agreed by the participant and by their Care Coordinator/Lead Health Professional;
- Be willing to be interviewed; and
- Have English as a first language

Potential participants were also subject to the following exclusion criteria:

- Not be experiencing active psychosis, delusions or mania;
- Not have a diagnosis of an autism spectrum condition.

The approximate median age, based on participants' self-reported age-range was 42 years. No psychiatric diagnoses were specified in the selection criteria, although participants spontaneously reported a wide range of mood and anxiety-related difficulties, including depression, psychosis, agoraphobia and generalised anxiety. Participants also had a mixture of out-patient and in-patient experiences prior to their current status as outpatients or recently discharged. The participants all described themselves as 'white British', and had English as a first language. Four lived in a rural location, and one in an urban area. The type of PS received varied and was not manualised; and comprised social support in the form of accompanying on trips out of the home, informal emotional and practical support, and simple interventions aimed at reducing subjective anxiety such as graded exposure,

structured activity scheduling and psycho-education about mental illness. All were parents or grandparents, and one was in employment, and two were in training with a view to becoming peer support workers at some stage. All participants were well enough to participate at the time of recruitment, to provide consent and be interviewed. All participants were recruited from the same service, across two different teams. Two participants worked with the same PSW ("Laura" and "Gemma"). Recruitment was facilitated by Peer Support Workers who were familiarised with the study and asked to approach any service users that fulfilled the criteria with an information pack. Individuals were then asked to make contact with the first author to discuss participation. Written, informed consent was obtained prior to interview. All participants were asked to suggest a pseudonym and provide demographic information to help contextualise the sample (Table 1).

Table 1. Sample characteristics

Identifier	Age	Location	Length of PS	Time in services	Previous help
Brian	51-65	Rural	6-9 months	3-5 years	Psychiatry, nursing.
Gemma	35-50	Urban	6-9 months	1+ year	Not answered
Laura	35-50	Rural	6-9 months	6+ years	CBT, groups, nursing, counselling.
Melissa	18-34	Rural	3-6 months	1+ year	Psychiatry, nursing.
Tina	35-50	Rural	9-12 months	6+ years	Psychiatry, nursing, psychology.

<sup>\*</sup>All names provided are pseudonyms to protect participant anonymity.

#### **Interview Procedure**

Participants were told that the interviews would be audio-taped and later transcribed. It was explained that transcripts would be analysed for themes to help develop an understanding of experiences of peer support from a service user perspective. Participants varied in their ability to spontaneously offer rich descriptions of their experiences, but all reported that they had found it a positive experience and were pleased to have had the opportunity to look back on and make sense of their experiences.

## Analysis

Following research group discussion, IPA was selected as the method of analysis due to this particular way in which its approach facilitates an understanding of phenomena that is both idiographic *and* contextualising, something which was felt to be particularly appropriate to the aims of this study in terms of developing an understanding of individual experiences of a contextualised, inter-personal psychosocial intervention such as PS. IPA aims to probe how individuals make sense, in their own terms, of lived experience, through the production of linguistically and interpretatively rich contextualised accounts. The idiosyncratic, experiential personal perspective of each participant is developed into interpretative accounts that strive to retain a balance between individual accounts and higher-order group-level themes through a creative, hermeneutic approach to interpretative analysis. Epistemologically, the approach sits part way between realist and constructivist positions beginning with the phenomenological and moving to the interpretative. While on the one hand it is rooted in the idiographic, it openly acknowledges that since participants' accounts are themselves acts of sense-making,

then IPA analytic process makes sense of this first-order sense-making; a process referred to as the "double hermeneutic" of IPA (Smith et al., 2009).

The general approach for IPA analysis described by Smith et al., (2009) was followed. Descriptive, linguistic and conceptual codes were identified within each transcript by the first author. Trustworthiness, and fidelity to the IPA method, was enhanced by supervisory discussions, and the involvement of the supervisory panel at group coding sessions. Once the codes were generated, the author sorted these into super and sub-ordinate themes, through another iterative and interpretative process, the process of which and the emergent thematic structure was discussed with the supervisory panel, again to ensure trustworthiness and fidelity within the approach.

#### Results

Three superordinate themes emerged from the analytic process. The first theme, "Power of Relationship" is principally experiential, with an emphasis on the often non-verbal, 'felt' experience. It has three sub-themes; 'lived experience as a subtle but powerful presence'; 'a felt sense of empathy', and "a sense of safety in flexible boundaries'. The second super-ordinate theme, a "Focus on Change", has a different, more action-orientated sense to the first and illustrates the importance of 'doing' to the participants' experience of peer support. It has two sub-themes, 'PSW as intermediary', and 'hope from doing together'. The third major theme is 'Psychological Impact', and mirrors the more reflective part of the participants' accounts as they begin to look to future and past, both reflecting on experience and imagining possible futures. It has three sub-themes, 'perspective change to symptoms', 'exploration of wellness identities', and 'growth from adversity'. In this

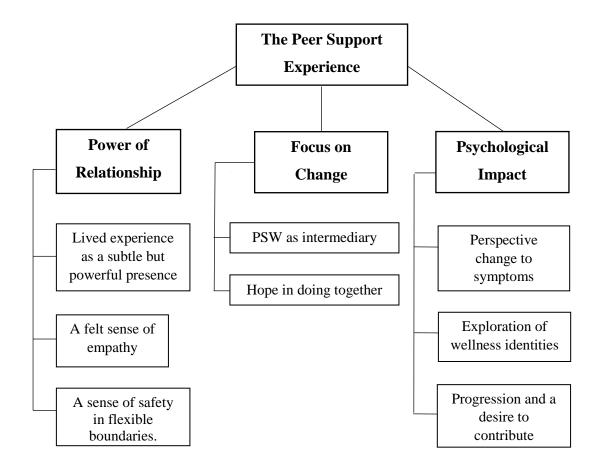
final theme there was a growing sense of self-acceptance and a readiness to move forwards and move on from the 'mental patient' role, towards an increasingly socially-orientated self, combined with an increased sense of a desire to contribute accompanied by an increased sense of compassion for self and others.

All the sub-themes are grounded in the individual accounts, and so through their analysis and development it has been possible to provide a strong sense of what mattered to the participants in working with PSWs and how their understandings of their experiences developed. A detailed examination of the themes is presented below along with supporting verbatim extracts taken directly from the interview transcripts<sup>1</sup>.

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<sup>&</sup>lt;sup>1</sup> Transcription note: The convention '...' is used to illustrate a pause in speech and '[...]' to illustrate where a piece of text has been omitted. All emphases in italics are participants' own.

**Figure 1**: Hierarchy of super-ordinate and ordinate themes.



Theme 1: The Power of Relationship

Lived experience as a subtle but powerful presence. All participants described a positive relationship with their PSW, and related this to knowing that their PSW had experienced or was still experiencing mental health difficulties. The impact of lived experience was most evident in the earlier stages of the relationship and acted as a "short-cut" to trust, and to confidence in the potential of the PSW to be of benefit. PSW disclosure varied in timing, content and style, but all participants portrayed a sense that the service felt tailored to their needs, even though these needs were not necessarily overtly discussed. This provided a strong sense of the experience of receiving disclosure as intuitively yet skilfully delivered, such that participants felt

that the shared focus of the work remained on them. The lived experience was described as a crucial part of the success of the relationship by all participants; and was described as levelling, cathartic and normalising, in the sense that participants experienced an internal shift because they suddenly no longer felt alone, as <sup>2</sup>Melissa explained:

Melissa: "Like you're not the only one experiencing it yeah it just makes you feel more ... I dunno just ... normal [laughs]. Not alone, probably. I just think cos I spent so long trying to cover up how I felt. Normal just means it's ok to like feel how I do sometimes."

One participant, Gemma, knew little in the way of detail of her PSW's story, which was what she had wanted; she just needed to know that the lived experience was there. As their relationship developed, based on the trust that the implicit lived experience provided, small amounts of her PSW's story emerged but only at moments that were relevant to her own experiences and at a point that would be directly useful to her. This example conveyed the skill and sensitivity of her PSW's approach and the sense that flexibility and inter-personal sensitivity may be relevant skills.

Another participant, Laura, described a sense of repeatedly 'forgetting then remembering' that her PSW had been through mental health difficulties. In her account, she made sense of this as positive and welcome, because it meant that perhaps others could not always see her difficulties either, suggesting sense of internalised shame about her own mental health symptoms. That others might not see her symptoms mattered to her because as she reflected on her peer support

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<sup>&</sup>lt;sup>2</sup> All names used herein are pseudonyms chosen to protect participant anonymity.

experience, she described the internal struggle she had faced between reconciling two personal identities, that of 'professional' and 'mental patient'. She was able to identify positively with her PSW on several levels: most important to her was that she was professional, competent and had lived experience, possibly suggesting that her PSW took on a role of mentor or role-model to her:

Laura: "She seems very... really *competent* ... with, with what she's doing that she doesn't just seem like a person who's suffered mental health issues [...] she's, she's been there herself but also ... she's got also sort of like really good approach and knowledge."

Melissa, who described herself as shy and someone who previously had never spoken about her mental health difficulties, experienced a strong sense of "permission to talk" in her PSW's confident and upfront style of sharing.

A Felt Sense of Empathy. All the participants described their relationship with their PSW using language (both verbal and non-verbal) that gave a strong sense of an embodied, felt response on hearing their PSW's story. Brian spoke of a physiological sense of 'shift' on meeting his PSW for the first time as he listened to her explain the PSW role and its relation to lived experience:

Brian: "[...] so she explained and as she explained it was like a dawning, inside, I suppose, like the sun coming up because it was totally different from anything else [...]. It was totally different, it was a big change, [...] I kind of, I relaxed straight away."

Brian also commented on a sense of warmth as a feeling that for him came from a sense of genuineness to his PSW's style:

Brian: "There was a feeling, that's why I say it came from inside, [...] that growing warmth. [PSW] treated me, you know, I like to be treated as a person. [...] she wasn't sort of oh Brian we'll help you she wasn't cloying. There was no artifice with her, absolutely none."

The four other participants also reported experiencing a physical sense of relief, again a kind of relaxation and easing of pressure, this time for not having to explain how they felt because their PSW had lived experience:

Tina: "No, you don't all the time, you know when you do meet new people you go through the same old thing [long sigh]."

Interviewer: "Oh that sounds tiring!"

Tina: "It is! You feel like a cracked record sometimes."

Similarly, Laura talked of a felt sense of relief in being understood based in the grounding quality of both partners having lived experience:

Laura: "So the *relationship* that we have got we've got really has developed [yeah] because I'm aware of all these things now and they can go unsaid they don't have to be verbalised it is sort of here [points to chest]."

A sense of safety in flexible boundaries. The experiential quality of the participant's account continues with the third sub-theme, in which all participants talked at length about how important managing boundary was to them in maintaining a sense of inter-personal security. All participants talked about the PSW relationship as not like a friendship but more than a professional relationship. Their accounts suggest that sharing of lived experience, and later non-mental health disclosures,

combined with non-verbal aspects of communication resulted in instants of felt connection, which they described as a deep sense of trust and safety.

Tina: "... whereas it's not like a friendship ... you don't sort of take it one step further if you know what I mean [...] because erm ... cos it's quite ... erm challenging to have friendships [...] because you know not everyone understands what it's like to go through what you're going through. That you don't feel that burden of a friendship if that ... that makes sense. You haven't got to ask would you like to come for a meal next week or go shopping."

Gemma described how humour was an important facet of their relationship and an example of a flexible yet boundaried dynamic. While they both enjoyed the humour, it was understood that her PSW did not let her use it to avoid challenge; giving a sense of flexible yet firmly present boundary:

Gemma: "But she understands, a lot of people don't but [PSW] does, not even my family she notices she knows that my humour is a bit of a cover up sometimes [...] that actually 'yes it is funny but right ok so she's scared', and that's quite reassuring that she understands me that well? [...] I'll start wanting to go home and I'm like let's get you home in the warm and I'll say that to [PSW] as if I'm her carer [laughs] so we have a little laugh but that we're doing everything that were meant to be doing. She's lovely [smiles]."

Laura described the flexible quality of her relationship with her PSW as being based on a mix of professionalism, the sharing of lived experience and small amounts of self-disclosure not relating to mental health. For Laura this combination gave rise to a sense of trust so strong that she talks of it in terms of a physical

experience, as she describes movingly the sense of being in such a "safe pair of hands":

Laura: "Guiding me. It's not ... I think there is [raises voice], I think there is a little bit of a sort of like [louder voice] "go up to the edge" ... sort of like "I'm behind you, just, just go to the edge. I am behind you" [motions with both palms upturned]. But sort of like I'm, I'm there to support you I'm there ... to ... I won't let you go over the edge, I won't ... I won't let you".

For Melissa and Tina, they both valued flexibility of boundary in relation to time-keeping, and both described having previously experienced frustration and a sense of inadvertently being 'brushed off' by time-pressured health professionals. At the same time, it was understood that their PSW's had other clients and would not *always* be available; what mattered was that unavailability was discussed candidly, which for them protected the relationship. This open and honest communication was contrasted with prior non-peer help experiences where appointments had occasionally been cancelled without explanation, which was experienced as a painful reminder that the relationship mattered more to them than to the professional.

Finally, four participants commented that for them connecting in ways that did not relate to mental health experience was an important part of establishing a relationship with their PSW. For Tina, having an opportunity to engage in "normal" chat as two mothers was normalising and deepened her connection with her PSW. Brian explained that his PSW knew he was on his own and that he "had no one to talk to", and her talk appears to have been transformative for Brian precisely because it was not about lived experience:

Brian: "[...] but to share part of their life with you, it's a *sacred* thing. It means a lot, it really is. It's something that's never happened before, that was massively important."

#### Theme 2: Focus on Change

Peer Support Worker as Intermediary. Three participants talked about the usefulness to them of their PSW facilitating communication with their mental health team, especially where their trust in non-peer professional help had been undermined by negative experiences. Participants also recognised that the relative severity of their mental illness itself made relationships with professionals more or less difficult, and that previous negative experiences of help coloured future experiences. Brian had recently witnessed compassionate care by mental health professionals and in comparing this to some negative experiences of his own when he was at his most unwell, he also wondered if his mental illness had made relationships with professionals more difficult. He wondered if having a PSW sooner would possibly have been useful. Brian, who had recently begun a PSW training course himself, made sense of these experiences by acknowledging that professionals do care but may be limited to some extent by the structural limitations of professional and organisational culture:

Brian: "[T]hey cared about the person too, you know, they had that, they were using their skills but their level of compassion for the person as, as a person was much higher than I thought it would be [ok] so it makes you think you know they do care, it's just that they go as far as they can."

Melissa specifically mentioned how her PSW would discuss mental health issues with her but use non-medicalised language. This was important to her

because the language used gave rise to a relaxed feel to their exchanges resulting in her feeling listened to. For Melissa, the use of medicalised language took her back to a frightening and lonely experience as an in-patient:

Melissa: "And maybe it reminds me of ... like when I was in hospital I didn't really feel then like there was anyone there that was just there to chat or anything there wasn't anyone really it was like you would [only get to] talk to people when you needed your meds."

During Tina's interview, she explained what it was like for her to have her PSW act as a "go-between" [her words] for her and the mental health team, and how by having someone act on her behalf she was able to recognise what was or was not acceptable, by watching her PSW and learning from how she managed difficult situations. She felt reassured that her PSW would represent her faithfully back to the mental health professionals, and that as a result her care had improved:

Tina: [...] cos I think they have their weekly meetings you know about everybody [...] and erm I think that helps as well because obviously one arm knows what the other arm is doing [laughter] and things like that if you know what I mean."

Four participants particularly valued the availability of, and accessibility to their PSW, which would not have been possible from their health professionals who they defended as "too busy and with lots of paperwork". Two participants also mentioned the importance of having a stable point of contact during periods of service re-structure and financial cuts, supporting the idea that their PSW's acted as a buffer to them during these organisationally unsettled periods.

Brian commented that he now enjoyed much better relationships with his mental health team and Melissa described a new relationship with a community psychiatric nurse that was going well. Both felt that this improvement was due to their symptoms having receded as a result of their work with their PSW. The reciprocal commitment participants described between them and their PSWs, appeared to result in improved engagement and a better sense of relationship quality with mental health teams.

Hope in Doing Together. All participants particularly valued the practical focus of their work with their PSW, and the focus on change that occurred through doing together where they found they could go further and achieve more than on their own. The focus of their shared talk tended to be on reflecting on progress, which kept the tone positive and helped sustain motivation to tackle difficult issues:

Laura: "And, she and she could show me by writing it down actually really did have something there concrete a record of what I've managed to achieve and say "look, go me!" I've managed to do [...] it was the first time that somebody had given me physical tools and done the approaches with me [...] and it felt like the first time I've ever had somebody *see* [her emphasis] what it's like for me."

Gemma described how she and her PSW spend time talking about progress, and how helpful this was because slow change can be overlooked, suggesting the act of shared noticing in itself builds positive feelings:

Gemma: "When some mornings, you know we look back on the work we did and a few months ago I couldn't even stand two houses away without triggers and now I'm walking [the school run]. You just do it over a period slowly over a period of time but yeah [smiles]."

Melissa described how progressively doing more with her PSW built a sense of momentum and motivation that enabled her to keep going, despite it still being difficult to do:

Melissa: "I just think I don't want to go back there where I'm at home doing nothing I want something to sort of focus on so it's more scary in a way to ... give up even though it's quite scary to go and do these things but I'd rather do that than be at home."

For Tina, going out with her PSW was something she looked forward to as a rare opportunity to do normal things, but also this relationship was something she valued because it was the only thing she felt was just for her. As if prior to this relationship she had not experienced a level of security where she could allow herself to be at the centre of their shared focus. The positive emotional impact of this appeared to bring a sense of hope and belief in the possibility that future goals which once seemed completely out of reach were more attainable, even if not immediately:

"It's ... I haven't had anything for just me and erm ... and I know that I do want to get well so ... you know going out and doing normal things is part of it. It's nice to be able to do it with somebody else you know [...]. I mean ... erm ... I do still struggle with supermarkets but umm ... she says we're going to have to go one day and I'm like ok."

#### Theme 3: Psychological Impact

Perspective change to Symptoms. Four participants talked of a growing sense of self-acceptance combined with a growing belief in their capability to "do despite". Brian, Tina, Gemma and Melissa described how their relationship to their symptoms had changed while Melissa had also noticed a reduction in symptoms:

Melissa: "I still like get really anxious it doesn't show as much anymore and I used to really shake and have panic attacks and haven't had a panic attack for ages like and ... erm but I still I'll get so I can't talk I still find it really hard to talk to people especially if there's a group but it definitely is getting easier."

Brian spoke of a growing feeling of distance from his symptoms of mental illness, which had come about in part because he was able to witness his PSW at work and doing well in her personal life despite still having times when she experienced symptoms. Brian's use of the second person was notable, possibly mirroring the shared noticing he and his PSW had done, reinforcing the sense of shift in perspective on his difficulties:

Brian: "[T]here are some times when those demons drag me back in and I have to erm like this weekend was one of them [...] but...now I know they will pass and before they didn't pass. They just used to last for ages but now I know that by doing a few things and managing how I feel, I allow myself to feel down [...] you're allowed to do that Brian, you can do that, and it will pass and you'll be fine."

Laura had also noticed that she could acknowledge her distress where previously it had been a solitary experience and in doing so she had noticed a growing belief that difficult days would not last for ever. Melissa spoke at length about how determined she was now to try to achieve what she wanted for herself even if she still struggled:

Melissa: "I knew that I was struggling but I never thought that I've got a mental health condition I dunno but yeah now I look at it differently and think that anyone can suffer from something mentally. It doesn't mean you can't do what you want to do umm yeah so I think I look at things differently."

Exploration of and Return to Wellness Identities. A process spoken of by all participants was the opening up of the self to the possibility of new, or lost, identities, either through trying new activities or through watching their PSW in their role, as if inspiration led to imagination. Throughout Gemma's account, her recovery mirrored a re-emergence of wellness behaviours linked to her fully inhabiting the 'proper mum' identity she felt she had not been completely able to do prior to her work with her PSW. She wanted to spend time on her hair and appearance now and made sure that she was up and dressed:

Gemma: "Yeah, it's still hard I still get that horrible feeling in my stomach but it's nice to have that stress again with being a proper mum what I say a proper mum come on let's do this, put a brush through my hair."

Laura's experience was different in that her occupational identity was previously understood by her to be mutually exclusive to her mental illness identity. Now she was able to reconcile these and see them as complementary, something she attributed to meeting her PSW whom she valued as a professional and for her lived experience. However, escaping the constraints of illness identities required courage and taking this leap required the "firm base" provided by their experiences with the PSW.

Melissa had lost her business and with it her occupational identity when she became ill, but through having a PSW and seeing for herself how this had been a positive role for her, she became curious and felt a desire to reconnect with that part of herself:

Melissa: "I hadn't considered it before I didn't even know it was available or anything [...] but then I just thought I got to the point if I don't push myself and get out of my comfort zone I'm not going to get on so yeah I just I don't know I just felt like it was the right time to do ... something different really."

One way in which this identity change appeared to happen, was that the PSWs created a safe enough space within which new or alternative identities could be tried. Their use of non-medicalised language and sense of genuineness was important to participants. Tina particularly valued how her PSW had shared some good news with her enabling her to move beyond the patient role, an experience remembered through a feeling of happiness:

Tina: "I mean yeah when she told me I smiled to myself and even when I put the phone down I was sort of oh that's lovely you know I'm really pleased for her err ... yeah I suppose it does lift your mood a bit to know that someone else is happy you know. [...] You don't always want to feel like the patient or that people have to be careful what they say around you in case they're worried about upsetting you."

Brian valued the naturalness of his PSW in her behaviour towards him, including through the every-day language she used, and through non-mental health disclosure. For him, this made him feel trusted by her, which seemed to lift him out of a version of self previously dominated by the patient role:

Brian: "[A]nd that was another way of ... that's support if you like because it's you know okay [PSW] trusts you enough [...] you're a grown man in a room and you can take care of yourself mate and that makes you think you do have to take care of yourself and you're there not as erm ... a patient, but as a person who can do things and it's expected."

Growth from Adversity. Three participants talked about how they were now able to look back on their experiences with a sense that while it had been awful it had provided new opportunities that they would not have otherwise have had the opportunity to take up:

Melissa: "[I]t's really great and to think that I've got something out of it that might, well it is part of my future like something erm ... that I can focus on ... like that. I never would have dreamt it could turn into something like that."

Brian reflected back on his life before his illness as almost belonging not only to a different time but to a different, more passive version of himself, and that his illness had been inevitable and necessary because without it then he could not be where he is now:

Brian: "[I]t was all just ... I nearly, I nearly said it was not me ... it wasn't the person I wanted to be it was just the person I was [...] It was inevitable, it was necessary [...] My recovery is for me to do, they're not going to do it for you and it changes that completely. The realisation was good ... absolutely you can do it yourself, thank you."

As recovery had progressed throughout their time with their PSW, there was also a gradual sense from the participants' accounts of wanting to give back or contribute:

Brian: "I don't want anyone to have to feel the way I did and feel alone, it's horrible, it sounds really worthy, but it's truly horrible."

This desire to contribute could be tangible and observable, such as deciding to train as a PSW, or occur as a change at an intra-personal level, and the ways in which this desire was expressed varied, possibly according to what was achievable within the constraints of participants' current situation and level of wellness: Gemma described an increasing sense of compassion towards others, and for her she could contribute by encouraging her children to be compassionate to others experiencing difficulty.

The desire to contribute through a growing sense of empathy and compassion and/or practical action, was another way in which participants could move beyond the patient role, a phenomenon that appeared to increase indirectly as recovery progressed via their relationship with their PSW.

#### **Discussion**

#### Summary

This study aimed to explore what it is like for service users to receive individual support for mental health difficulties by a PSW employed within an NHS community adult mental health team. The findings add to current understandings of what is important in successful peer support because, they are focused on the service user perspective. In addition, the use of IPA brings a depth of interpretation greater than is possible with less idiographic qualitative techniques. Semi-structured interviews were conducted by the first author (LM), who had no prior connection to

any peer support programme, and the analysis resulted in three super-ordinate themes.

## **Power of Relationship**

Theme one, "The power of Relationship" illustrated the ways in which the sharing of lived experience was experienced by the participants, how the early moments of relationship were experienced at a pre-reflective level, and how the construct of 'professionalism' is a negotiable phenomenon which both PSW and service users co-construct to maintain a sense of relational safety. There was evidence to suggest that for some individuals, the relational trust developed through disclosure may facilitate a process of positive social comparison in which the PSW is perceived by the individual to possess characteristics that go beyond similar experiences of mental health but are nonetheless of subjective importance to that individual, such as a similar level of education or social background. There were a number of benefits arising out of this quality interpersonal foundation including normalisation, a levelling of power, and inspiration from positive comparison bringing a sense of hope and optimism in the possibility of this help being truly different and therefore more helpful. The sharing of lived experience appeared to be cathartic for some participants, both to hear someone else talk openly about it, and for them to discuss their own experiences. Participants all reported a sense of reduced isolation and loneliness; emotional states secondary both to their mental illness, but also apparently to the experience of self-stigmatisation, suggesting that the sharing of lived experience may act as a catalyst for change by facilitating a reflective period of re-evaluation preceding a more change-oriented phase. These findings are consistent with recovery literature emphasising the importance of

quality relational contexts to promote recovery built on an awareness of the importance of power, vulnerability, exposure, dignity and respect (Repper & Perkins, 2003). These findings are also consistent with the psychotherapeutic literature on the "core conditions" necessary to form effective therapeutic relationships; empathy, non-judgemental warmth and genuineness (Rogers, 1957), and give support to central importance of quality of relationship in work with vulnerable individuals.

The findings also suggest that for at least some individuals there may be a role modelling aspect to PS, in which comparisons are made about not only similarity of experience, but similarity of education level or social class, or social role such as being a parent. Festinger (1954) argued that through processes of social comparison with others, we make use of information from them for "self-improvement" (Wood, 1989) when we perceive them as similar and yet further ahead along the way to achieving a shared goal. The period of reflection preceding outwards change may comprise such moments of social comparison and social connection through perceived similarity, and future research could explore the dimensions on which comparisons are most fruitful to effective PS relationships. Finally, the findings support the principle that the desire for social connection does not disappear with mental illness, and that relationships can be established if the conditions are suitable, something that has previously been commented on in the mental health inclusion literature (Davidson et al., 2001b).

#### **Focus on Change**

The second theme, "Focus on Change", and its two sub-themes ("PSW as Intermediate" and "Hope from Doing Together"), explored how participants made sense of the effect of the more practical elements of their work with their PSW.

Interfacing with mental health teams was highly valued by participants but not just because of the practical benefits of having a representative within their mental health team who could action change. PSW's appeared to span the inter-personal chasm between service users and their mental health teams, and shielded service users from a fear of negative evaluation or interaction (especially where there was a history of such experiences). Participants valued the sense of protection offered and the space and time it bought them to progress in their recovery sufficiently to then later take back independent self-advocacy. This finding is consistent with recent studies which also reported that PSWs act as advocates to interface with mental health teams (e.g., Gillard et al., 2015), suggesting that sometimes organisational stress can undermine the capacity for mental health professionals to provide the level of support needed by the most unwell patients. Implicit in this observation is that relationship security and wellbeing is not something only for patients, but is needed throughout an organisation for its members to consistently provide emotional support to vulnerable individuals. Secondly, PSW's maintained a positive focus on change and progress, and participants, in their increasingly reflective accounts, began to recognise the sense of relief this engendered possibly because it created a sense of "breathing space" within which they could begin to explore beyond comfort zones, notice improvement and consider the possibility of alternative futures.

## **Psychological Impact**

Finally, in the third theme, the psychological impact of their peer support experiences was reflected in the participants' increasingly reflective, interpretative accounts. An increasing sense of psychological distance from their mental health symptoms appeared to combine with a desire to re-connect both intra-personally and

through new activities with others. This "perspective-gaining through socialisation" process appeared to be supported by the opportunities offered within the peer support relationship to experiment and practice behaviours associated with identities beyond that of "mental patient". Some participants were able to move beyond illness identity by providing support to their PSW or sharing in and enjoying their successes, while others began to imagine how they would now show increased compassion to others, suggesting that they had begun to visualise themselves in helping rather than helped roles. This increasing sense of a turning back outwards to the world and to others supports existing understandings of mental illness as a biopsychosocial phenomenon, in which illness symptoms lead to isolation, which in turn exacerbates and maintains illness. This study enriches this knowledge by providing additional evidence of the internal experiences of recovery in peer support prior to the outwardly observable changes, such as social connectedness, which may be better understood as distal outcomes of earlier, internal processes at work that begin within the framework of a successful peer support relationship.

#### **Clinical and Theoretical Implications**

Overall, our findings present a picture of peer support as an emotionally rich encounter for service users, where moments of reflection and re-evaluation emerge spontaneously from being with someone who fundamentally understands what it is like to be mentally unwell and what helps because they have been there. The value of relationship over 'intervention' has been evident throughout the findings, and suggests that beyond PS initiatives, creating positive relational contexts within which recovery can be facilitated is of systemic importance and need not be limited to

therapeutic contexts, but should potentially be considered top-down in the design and running of effective mental health services.

Disclosure appears to act as an invitation to belong, and therefore from the earliest moments, when peer support works well, it acts to reduce the isolation that feeds off shame and stigma. Resource-focussed language and the ability to maintain a practical thread throughout their sessions means that PSWs effectively "coach" their service users towards self-management. The co-creation of a safe relational space within which service users can address previously too-difficult issues, observe and learn from their PSW's successful self-management of symptoms, and experience a consistency of connection over time together may facilitate the necessary changes for recovery to occur. Our findings also suggested that the quality of relationship was characterised by skills of empathy, warmth and acceptance redolent of the so-called "core conditions" of successful therapeutic relationships (Rogers, 1957). Indeed, in Repper and Perkin's (2003) model of social recovery, they argue for interventions that are based on quality relational contexts built on an awareness of the importance of power, vulnerability, exposure, dignity and respect. The positive experiences of PS in the present study suggest that when it works well, PS is an intervention which fulfils such criteria.

Our study also supports previous findings that disclosure of lived experience may act as a kind of "short cut" to the establishment of relationship especially where self-stigma (the internalisation of wider negative discourse) and associated fear and shame impedes the formation of new relationships (Corrigan & Deepa, 2012). PS as an intervention may therefore be one way to provide the safe relationship within which such barriers to engagement and recovery can be

overcome. Indeed, the impact of such issues on engagement arguably underlines the importance of maintaining organisational awareness of sociocultural difference and issues of power within mental health services. This may be particularly important if such differentials serve to perpetuate illness identities that may weaken the individuals' potential to achieve successful recovery, as is suggested by some of our findings. Consideration of how to mitigate such differences in the absence of disclosure could form the basis of further research, although current literature on recovery may be relevant such as increasing service user involvement in the design and running of mental health services.

These findings may have implications for how peer support is understood but also for how it may be evaluated and how services are designed, because they suggest a prospective outline for a model of peer support based first and foremost on the quality of relationship underpinned by therapeutically useful disclosure of lived experience, and appreciation of PS-specific factors such as informality (of language, setting). Moreover, if relationship is key, then this suggests that PS may work when the PSW offers empathy, positive regard and genuineness (Rogers, 1957), indicating a potential focus for more process-focused PS research programmes. Such an approach is not intended to suggest that it be viewed as distinct from other sources of help, indeed to do so would be deeply unhelpful and run the risk of missing an opportunity to develop a framework of helping for services in which professional support and PS are part of a continuum of different help that a person may receive, depending on where they are in their recovery. Indeed, Barker and Pistrang (2002) argue that any separation of non-peer professional and peer sources of help is "unnecessary and unproductive" (p. 362), both in terms of implementation at service level, and in the development of theoretical understandings. They argue for a return

to the study of 'process' in psychotherapeutic research over outcome as a means to bridge the gap between non-professional and professional sources of help; a stance that would emphasise the importance of relationship to all inter-personal interventions be they formal or informal. However, linking process events with eventual outcomes, especially in a causal manner, is not straightforward or easy to define, probably because contextual variables such as timing of delivery may be important mediators. Indeed, meta-analyses of outcome evaluations of PS have painted a somewhat confused or contradictory picture (Lloyd-Evans et al., 2014), but it does not necessarily follow that PS itself is ineffective if evaluation studies have missed what is important by focussing on end-point outcomes.

Another argument for integrating understandings of PS with other forms of help is that there may be important benefits for both patients, peers and professional staff in breaking down artificial barriers between these groups, not least in terms of unconscious or conscious stigma, but also in terms of efficiencies for services and opportunity for mutual learning. Studies of peer support in physical health have examined the peer-professional interface in terms of benefits to both parties as well as benefits to service users, and suggest that where peer and non-peer professional help are actively encouraged to work together to co-deliver interventions, health professionals reported learning from the volunteer's experiential knowledge, while volunteers valued the enhanced opportunities for their own personal and professional development that came out of enhanced social co-operation (Curtis, Woodhill & Stapleton, 2007).

While not new as such, this study's findings add depth to existing understandings because of the experiential focus on service users emphasised by the

idiographic and phenomenological focus. The findings have suggested that evaluation of PS at service level could perhaps take into consideration both internal and external changes as measurable outcomes consistent with known outcomes of recovery. For example, it may be useful, at service user level, to include both a measure of self-stigma and of wider social functioning in future evaluations of PS. It has also been argued that future research may benefit from a return to a focus on researching process as well as outcome, not assuming that clear links can necessarily be made between the two, that contextual factors be taken into consideration in determining when it is the right time to deliver PS and under what conditions, and that peer and non-peer professional help be integrated where possible along a spectrum or continuum of help reflecting the different needs of individuals at different times.

Finally, the service user perspectives provided in this study posits a role for empathy as a kind of shared, imaginative social understanding that may represent a link between the early peer support relationship and later more observable outcomes. Further research on the therapeutic impact of empathy on mental health difficulties in the context of peer support may develop our understanding of the process of change in successful peer support.

### Strengths and Limitations of the Study

The focus on the service user perspective is a key strength and novelty of this study. The use of IPA allowed for more in-depth meanings, and captured the heterogeneous nature of the experiences rather than generalising at too early a stage of knowledge. In addition, the IPA was carried out with a consistency of commitment to trustworthiness, fidelity to the approach in terms of epistemology,

and there was a clear attempt to be both idiographic and interpretative in accordance with guidelines for quality IPA (Smith, 2011).

One important criticism of this study is that its recruitment process of accessing participants through PSWs has resulted in a sample for whom peer support was an overwhelmingly positive experience. The fact that two participants were involved in PSW training may have added to this. PSW might not work for everyone, and a larger number of participants may have allowed for more negative findings, although unfortunately recruitment was limited by time constraints. In addition, a social desirability bias may have further skewed the findings towards the positive; participants may have felt disinclined to provide negative comments for fear that these may get back to their PSW. Finally, the PS delivered was not standardised, and it may have been useful for participants to have received a standard amount or type of PS, although equally this would have not been representative of the individualised nature of PS. Future studies involving service-users as co-researchers may have more success at accessing a broader range of experiences.

Inevitably, our findings are inevitably contextualised and therefore generalisation is limited. However, given that individualised, peer support delivered by employed and paid PSW's is expanding as an intervention throughout the United Kingdom and beyond, its conclusions should resonate for similar peer support programmes within statutory settings. Further research is needed to determine to what extent our findings are more broadly representative of service user experience.

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#### **Declaration of conflicting interests**

The study was undertaken in partial fulfilment of the first author's (LM)

Doctorate in Clinical Psychology, at the University of East Anglia. The contributing author (DW) at the time of recruitment was working within Norfolk and Suffolk NHS Foundation Trust as Clinical Psychologist within one of the Recovery Teams within which two participants were recruited.

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# **Extended Methodology**

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## **Extended Methodology**

The following extended methodology section elaborates on the information presented within the original research paper and provides additional information that was not included due to space limitations. A detailed rationale for the specific qualitative methodology chosen is presented, including the author's reflexive stance in relation to the study topic, as well as a consideration of functional reflexivity in relation to the possible impact of the choice of methodology, and its suitability for the research question. A preliminary critique of the chosen method is presented as a basis for further exploration of these issues put forward in the Critical Evaluation.

In addition to the above, detailed descriptions of the participants, recruitment procedure and data collection, including the design and service user involvement are included. The procedural steps of the analysis are detailed, along with a consideration of the quality assurance steps undertaken, and a description of the relevant ethical issues.

The aims of the current study were to address the gap in understanding about service-users experiences of receiving peer support and in doing so to contribute to discussions about possible underlying mechanisms, and finally to improve understanding of what is perceived as helpful or unhelpful in peer support interactions by those who are in receipt of such support, with the research question: "How do service users experience and make sense of working with a Peer Support Worker?".

# Methodological and Design Rationale

Ontology, Epistemology, and Rationale for Qualitative Research

Ontology is a sub-branch of metaphysics which focuses on the nature of existence, or what things are. Within this broad definition, different ontological positions exist along a continuum between realism and relativism. Realism posits that reality is independent from the human enquiry that enables us to "know" of its existence, whereas relativism states that reality is entirely dependent on the thinking that describes and defines it. Ontological position is therefore relevant to questions of methodology because, if we assume a realist ontology, this compels a methodological approach based on the discovery of discrete objects or beings already in existence "out there". Conversely, inhabiting a purely relativist, interpretational methodological position would invalidate the aim of producing "findings" as discrete units of knowledge because what is seen to exist is inseparable from the process of research itself and its socio-cultural and historical context (Braun & Clarke, 2013).

Epistemology, is also a branch of metaphysical enquiry but is concerned with what counts as knowledge and the underlying assumptions we hold as we come to know something. Just as there are different ontological positions one can take on a continuum, so there are equivalent epistemological positions. Positivism sits at one end of this spectrum, and constructionism at the other and contextualism sits in the middle. Contextualism, as an epistemology, states there is a knowable truth but our sense of it can only ever be provisional and situated because it is inevitably bound up in the social context in which the act of research occurs (Madill & Gough, 2008). Consequently, epistemology and ontology are distinct yet intertwined, and can be illustrated by asking "how do I know what I see is how things really are?"

**Rationale for IPA**. Interpretative Phenomenological Analysis examines how individuals make sense of personal, lived experience, and has been described as a framework or an approach rather than simply a method (Braun & Clarke, 2013), because it engages at a relatively deep level with questions of epistemology and ontology. This approach makes it ideally suited for research in which the focus of interest, or research question, is on the personal, subjective experience of sensemaking within a particular context, such as that which may occur during a psychosocial intervention such as PS. In its analytic process, it begins with the individual account but goes beyond this by moving from the "particular" to the whole, and in doing so acknowledges the paradox central to personal experience which is that all experience is simultaneously "embodied, subjective and perspectival" (Smith, Flowers & Larkin, 2009, p. 29). As a result it is a contextualising and idiographic approach that takes experiential phenomena as its building blocks of analysis; a combined focus carried through into the final interpretative account which simultaneously presents overarching themes directly arising from the data and embeds them in an account that positions them in relation to psychological theory. IPA posits that the researcher inevitably has to interpret the sense-making in the participants' accounts, making it a second-order interpretative exercise. In this way, the hermeneutic aspect of IPA therefore becomes a "doublehermeneutic", or a making sense of other's sense-making (Smith & Osborn, 2003). Therefore, successful IPA strikes a balance between all three elements: it retains an idiographic focus by ensuring the individual elements of experience are given sufficient space within the write-up; it is phenomenological because it focuses on the experiential minutiae of experience, and is interpretative because it does not assume meaning is inherent in accounts per se, but that through analysis the meaning can be facilitated to emerge as it is interpreting through the lens of relevant psychological frameworks.

A more detailed explanation of these three elements is provided below to further clarify the rationale behind choosing IPA for the present study.

**Phenomenology.** Phenomenology is the philosophical study of "phenomena", or things as they appear to us and their meaning or significance as we consciously experience them. Therefore phenomenological philosophy as applied to psychology means the research approaches that use its underlying principles as a framework focus on people's perceptions of their world and how they make sense of it. It therefore is about experience, but also the process of *thinking* about what it is like to experience the object (Finlay, 2016), and thus to "be phenomenological" in research is to also engage with the active and the intentional of conscious meaningmaking.

Phenomenology's concerns have developed from Husserl's early critique of the problem of objectivity in empirical science, in which he resisted the dualism of subject and object inherent in science and positivism (Langdridge, 2007).

Phenomenologists argue that claims of objectivity assume a realist epistemology and in doing so omit to acknowledge that even an object separate from perception, and therefore "objective", is inevitably filtered through the scientist's pre-existing structures of knowledge and experience. IPA's idiographic focus and its pragmatic use of reflexivity and bracketing are based in these ideas because they encourage researchers to bring to conscious awareness an appreciation of their own subjectivity in the research process.

Relatively little is known about how peer support is experienced by its recipients. The use of an explicitly phenomenological approach is therefore appropriate given the exploratory nature of the present study.

*Hermeneutics.* Hermeneutics is theory of interpretation, and is concerned with how we work with context and how to access original meaning through language or other aspects of sense-making. In this sense it can be said to interpret the "concealed meanings revealed by phenomenology" (Bäckström and Sundin, 2007, p.244), and in this way relates to the Heideggerian idea of the influence of past on present, inter-subjectivity and the central idea that we come into being within a social world comprised of these elements ("throwness"). IPA is hermeneutic because it concedes that accessing experience is only possible through the participant's sense-making of their experience, which in turn is interpreted by the researcher; and is at its most visible in the interviewing and analytic phases. It is also visible where in at deeper levels of interpretation an author uses the "heuristic devices" of conscious experience: self-awareness, embodiment, spatiality, temporality, intentionality, and inter-subjectivity (Fuchs, 2013), depending on the content of the accounts. The interpretative phase of IPA is not a linear process because inevitably as we consider the part-whole relationship, new meanings emerge that exert influence on these constituent parts. In a sense therefore, the interpretative aspect of IPA embodies the tension inherent in the methodology's underlying epistemology, that at one level we return to the "things themselves", but recognise simultaneously the unlikelihood of doing so successfully. It can be argued that in an attempt to reconcile this tension, IPA uses this iterative, "hermeneutic circle" to link the particular to the whole, and in exchange for this pragmatic solution attempts to offer up a level of interpretation potentially not accessible to the participant

themselves. How successful IPA is, as a methodology, in attempting to do this will depend to a large extent on the quality of the interpretative account provided and also on the richness of the individual accounts. Finally, a hermeneutic approach is appropriate to the current study because how participants make sense of their experience is as important to our understanding as the nature of the experiences themselves. Indeed, a participant's sense-making in a way represents aspects of their subjectivity, and is the filter through which the positive intentions of peer support are perceived as more or less helpful.

*Idiography.* IPA is idiographic in its focus; it prioritises the individual account over seeking to make generalizable laws to predict human behaviour. Smith, Harré, & Van Langenhove (1995) argue that there is a self-defeating flaw of logic where empirical, nomothetic approaches use aggregated data from many individuals to make predictions about single individuals. Therefore, it can be argued that smaller-scale studies, or even individual case studies can provide an important means of theory checking through the detailed examination of standard or anomalous exemplars (Swanborn, 2010). In this way, such approaches can be understood as complementary rather than distinct from nomothetic approaches. Similarly, IPA's focus on the individual does not exclude the possibility of making generalisations, but the type of generalisations are qualified through explicit attention to context and particular approaches to sampling. Furthermore, because IPA's phenomenology emphasises the situated, inter-subjective nature of experience, its outcomes are necessarily also situated, but in engaging with the individual we seek to illuminate their idiosyncratic, personal perspective of what it is like to be "in-relation-to" [a phenomenon] (Smith, Flowers & Larkin, 2009, p. 29).

An idiographic approach such as IPA, is appropriate to the present study because the aim is to explore participants' individual experiences, and to do this without any *a priori* assumptions that such experiences represent a commonality of experience, or that some aspects of the experience have inherently more value or meaning than others. In other words we begin by being open to the experience as conveyed to us by the participant; and to "return to the things themselves" (Husserl, 1925, as cited in Langdridge, 2007, p. 18). By working through our own presuppositions, we hope to be aware of them, and through this awareness attempt not to impose a hierarchy of meaning, but to explore in rich detail all aspects of our participant's account (later interpretative phases being separate). IPA's approach is also more appropriate to the aims of this study than less idiographic qualitative approaches, such as thematic analysis or grounded theory because to use those would respectively be epistemologically incoherent or require a more developed knowledge base around peer support than is the case.

In conclusion, the aim of this study was to explore the experiences and sense-making about experience of individuals working with a peer support worker. The lack of consensus on how to conceptualise the dynamic suggested a methodology that would enable a deeper exploration of what was predicted to be a complex [interpersonal] experience situated within a particular context. Therefore, a qualitative framework was appropriate because it matched these aims and was consistent with the researcher's belief in the importance of "giving voice" (Braun & Clarke, 2013) where certain stories tend to have to fight harder to be heard than others. IPA was chosen as a framework for analysis, after deliberation on the research question, and what approach would be best suited to answer it, along with the degree to which this choice would be consistent with my epistemological and ontological stance. The

deciding factor in its favour was the sense of internal coherence within IPA due to its emphasis on contextualised interpretation *and* its transparent engagement with the role of the researcher in the interpretative stage. The concept of the "double-hermeneutic" (Smith & Osborn, 2003) was particularly convincing and provided a stronger sense of a sustained thread from research aims, to epistemology, to data collection and analysis. Choosing IPA over TA was therefore in a sense based on these positives as well as more prosaic, but equally important, considerations such as the existence of a clear guidelines to analysis, and a good range of accessible literature to support evaluation of quality.

#### Method

## **Participants**

Four females and one male were recruited, aged between 32 and 60, all resident in Norfolk, in the East of England. Five of the participants lived in rural or semi-rural locations, and three were in receipt of secondary mental health services at the time of interview, and three had recently been discharged. Two of the participants had recently begun training as a peer support worker. Potential participants all had at least approximately six hours of peer support, and had all received clinical support such as visits from a community psychiatric nurse or review meetings with a psychiatrist. None of the participants were in receipt of inpatient services at the time of interview, and were judged by their peer support worker and care co-ordinator to have capacity, not be in crisis and be well enough to take part.

#### **Materials and Procedure**

**Design.** The study was devised and conducted within the framework of idiographic, qualitative psychology using a small, purposive sample. In-depth interviews were

carried out using a loosely, semi-structured approach facilitating the generation of rich, contextualised, first-hand accounts. Verbatim transcripts were prepared and analysed using Interpretative Phenomenological Analysis (Smith, 1996; Smith, Flowers & Larkin, 2009).

**Interview Schedule.** The interviews were conducted, audio-recorded, and transcribed verbatim by the author, and the interview guide (Appendix C) was designed with the aim of supporting a free and comfortable interaction. This was done by providing open-ended and non-directive prompts, which would help participants to begin but would allow them to take their reflections where they wished based on what was important to them (Smith et al., 2009).

During the interviews themselves, relatively more importance was based on developing a good rapport with the participants than following the schedule, and this proved more conducive to the generation of rich data than sticking rigidly to any predetermined schedule. The interview guide was nonetheless offered for feedback to a service-user research panel during the study development phase, which provided comments and points of clarification. It was also discussed in a qualitative research forum with other students, under supervision, at the host university.

Recruitment. Service managers were initially approached with a letter of introduction (Appendix D), and given an information pack comprising participant information sheet (Appendix E), consent form (Appendix F), demographic information form (Appendix G) and study poster (Appendix H). Next, peer support workers were contacted via the service managers and were introduced to the study via email and then at a group supervision attended by the author, and provided with the same study information pack. They were then asked to identify all supported

individuals who met the inclusion criteria, and give each individual the participant information sheet and consent forms. Potential participants who expressed an interest in participating were then asked to contact the researcher by telephone or email directly to discuss participation, and arrange for the study author to contact them by phone. Potential participants were then contacted and provided with the opportunity to ask questions and if still interested were booked in for their interview. Verbal consent was obtained initially and then at the scheduled interview date, formal written consent was sought and obtained.

The potential for bias was considered during the design of the recruitment procedure, and while it was acknowledged that in-direct recruitment via peer support workers could lead to a biased sample, this had to be weighed up against pragmatic considerations of time and the likelihood of successfully navigating ethics approval, and the risks involved in approaching individuals directly who may find such an unsolicited approach detrimental to their emotional well-being. To circumvent some of the potential difficulties, the aims of the study were clearly explained to the peer support workers, and reassurance was provided by the peer support coordinator. During the early stages of proposal development, the author met with a peer support worker and discussed these issues and the idea for the study more broadly.

**Sample Size.** Larkin (2013) argues that "how many participants?" is not the correct question for qualitative research, but instead suggests asking "is the data sufficiently rich to answer my question?" For IPA, most relevant in consideration of sample size is one's prioritisation of case-level discussion versus the interpretative phase, and the richness of the interview data obtained (Pietkiewicz & Smith, 2014). In addition, the institutional context within which the research is carried out has some relevance

where perhaps the dominant methodological orientation of the academic department is more quantitative, as well as the ease with which one is able to recruit at all.

Therefore, final decisions on sample size in IPA can appear somewhat arbitrary, but Pistrang & Barker (2012) explain IPA's typically lower sample sizes as a result of its particularly in-depth, idiographic focus on individual participants (compared with thematic analysis). Similarly, Smith argues (Smith, Flowers & Larkin, 2009) that smaller sample sizes in IPA are appropriate and justifiable so that the researcher can focus on individual experience without becoming overwhelmed with data, especially where time and previous experience in IPA is limited; for these reasons he recommends 3-6 participants for a clinical doctorate thesis; this study recruited 5 participants.

Sampling. The heterogeneity of a target population and the selection criteria are further issues to bear in mind. Typically, the ideal sample for IPA student research is relatively homogenous in terms of demographics such as age, gender, or location and homogenous in terms of project-specific criteria, such as length of time as a user of mental health services. The intention is that by controlling for demographic and social factors the psychological variability within the sample is facilitated to emerge, and the core phenomenological "objects of concern" can be identified (Smith et al., 2009, p.47). While this project followed this approach, some variation was inevitable given the need to recruit within a specified time-frame and the ethical importance of allowing individuals to participate, where contributing to original research was viewed by them as an important part of their recovery. Furthermore, it is arguable that because IPA is primarily idiographic in its focus, some degree of heterogeneity in the sample only reflects the deeper differences that may emerge through attending to individual cases first and foremost as individual experience is

prioritised. Demographic information forms (Appendix G) were completed by the participants to identify structural differences and similarities, such as time in secondary services, and therefore contextualise the sample. Sampling issues which may have influenced the data are discussed in the critical review chapter, for example, it was assumed that peer support workers were more likely to approach service users with whom they predicted the experience had been a positive one.

# **Ethical Considerations**

The ethical guidelines of the British Psychological Society (BPS) Code of Ethics and Conduct (2014) were followed, and NHS ethical approval and local R&D approval was sought and obtained (see Appendix I and Appendix J). Consent was sought at several points during the recruitment and interview process consistent with the idea of "processual consent" (Rosenblatt, 1995). For example, verbal consent was sought initially and this was followed at least 48 hours later by written consent and then by emphasising the voluntary nature of participation and explaining the right to withdraw without providing a reason to remove any sense of coercion. In addition, ample opportunity to ask questions was given and actively encouraged throughout the consent-seeking process and then during and after interview.

Confidentiality in relation both to risk of harm to self and others was explained during the initial phone conversation prior to verbal consent, and again when obtaining written consent at interview. For example, participants were made aware that if they disclosed anything which implied risk of harm to themselves or to another person, that the relevant individuals responsible for their care within the mental health team would need to be informed, following discussion with the research supervisor, and wherever possible the participant themselves. Due to the

focus on subjective experience and meaning-making, IPA studies can mean that participants engage with existential and/or deeply personal issues. The researcher therefore took extra care to orientate her awareness towards the well-being of participants and explained her role as a researcher and her duty of care to direct them to sources of assistance if they required extra support.

All personal information, including demographic questionnaire responses, and interview recordings, were stored according to Data Protection Act (1998) guidelines. Interviews were recorded digitally and transferred as soon as possible after interview to a password-protected file at a secure location. Participants were asked to choose a pseudonym to protect their identity, consent was sought and obtained to use direct quotes and the impossibility of guaranteeing perfect anonymity in qualitative research was explained more than once during the consent process.

The ethical impact of the study was also considered carefully in relation to the peer support worker, and care was taken to explain the aims of the study to them, given their role in recruitment, and more importantly from a duty of care perspective in relation to the potential impact of a perceived sense of evaluation on their ongoing recovery. During the initial stages of preparing the project proposal, the researcher met individually with a local peer support worker to discuss the idea for the study. The peer support worker was positive and fed back that in her opinion most peer support workers would feel reassured by being provided with a clear summary of the goals of the research. This information was then later provided to, and discussed with peer support workers in the recruiting area, in person and in writing. However, despite these precautions, recruitment was more problematic (initially) than predicted; and is discussed within the Critical Evaluation.

Participants were offered a £10 shopping voucher for a shop of their choice, at the end of the study. The issue of inducement was considered carefully, and through supervisory discussion, it was agreed that this small amount would not constitute inducement, but would be a small token of appreciation to the participant for their contribution, consistent with the Health Research Authority's guidance on Payments and Incentives in Research (2014).

# Researcher's Own Ontological and Epistemological Position

In relation to methodology, and in particular within the social sciences, such philosophical questions matter because they underpin what counts to us as reality, and what we take to count as knowledge. Our position directly shapes the questions available to ask, which in turn drives the selection of the appropriate methodology, and finally, the kinds of knowledge produced. By engaging with these issues, we can be more alert to the possibility and potential of our research choices playing a part, potentially, in challenging prevailing discourses that may perpetuate inequities against marginalised groups, or conversely objectifying others through defining their lived experience based on pre-conceived notions or stereotypes. To me, this seems particularly prescient to mental health research where prevailing explanations about illness and wellness have the potential to objectify and reduce the "ill other" to a set of diagnostic criteria or conversely, to facilitate alternative self-constructs that exist more independently of others' pre-conceptions.

As a white, female, Trainee Clinical Psychologist, working within the NHS, and who has not used secondary metal health services, I considered my personal stance in relation to the project, in particular my views on PS, and how they could influence my approach to undertaking the research study along its different stages. I

was concerned that participants may not feel secure enough with me to disclose negative experiences during the interviews if I did not take sufficient care in explaining my role as a researcher and my independence from their respective CMHTs. To mitigate for this, I worked hard in my communications to make my role as a researcher clear and as one without a vested interest in outcomes. Before embarking on this study, my only prior experience of PS was while on a training placement within an adult Community Mental Health Team (CMHT). While there, I had informally met with a newly recruited PSW who had explained how difficult they had found being the sole PSW within a team for whom "recovery" was still a relatively new concept. It was evident that both they and the team were very much in a period of adjustment to what the role would be and potentially how it may impact on the team dynamic. I remember being struck at the time that this PSW appeared to quite vulnerable within this team and I had had some concerns about how supported or welcome she may or may not feel, and so had some questions ibn my mind about what a PSW might need from a team to flourish in the role. Beyond this however, I had no firm opinions on the usefulness or otherwise of the role, apart from that it felt encouraging to see some increased patient choice around types of support available.

In developing early ideas for the study, I was drawn to the opportunity to develop my qualitative research skills as much as I was open to the opportunity to research in an area I had no previous experience of. I was however aware that in my preliminary readings about PS and the recovery movement, that I was not entering a politically neutral arena. I noticed my intention to use my own relative neutrality in relation to the subject matter to approach the project with an open mind and therefore in terms of shaping the project, it was this position of 'active neutrality' that was

most present in my approach and in my open and curious style during the interviews, and during analysis. Personally, I held beliefs about the importance of recognising the strengths and resources of the people I have worked with during training, and empowering them to make their own way through their difficulties in whichever way that made sense for them in ways that would be sustainable beyond formal therapy. This open-minded and relatively neutral position was something I was both aware of as a potential positive, but at the same time I was aware that I would need to use supervisory discussion to talk through my thoughts and feelings about PS as the study progressed.

My clinical work as a Trainee Clinical Psychologist incorporates life experiences, coping strategies and ways of making sense into understandings of individuals' difficulties, and therefore in a sense could be described epistemologically and ontologically as "critical realist/constructivist". This provides a context to help understand my researcher "position", which also reflects my underlying philosophy or value-system, and helps situate my preference for qualitative, inductive approaches. Jean-Paul Sartre (as cited in Schroeder, 2005, p. 232) argued that when we scrutinize others, objectifying them through the automatic use of stereotyping as we attempt to make sense of them in relation to our self, we create a social identity for that person based on our own definitions and not theirs. While this need not necessarily be pathologising, and can be therapeutic, an awareness of our own pre-suppositions is clearly an issue to actively consider when working in mental health.

From initial development of the research question through to analysis and interpretation, my relationship to the study and to psychological research in general

has felt porous as I have gone through clinical training. My emergent professional identity has shaped my personal identity, and the two have fed into my growing understanding of why I chose to embark on a qualitative research project within peer support. This process also occurred within the context of all earlier experiences, and it is only through this bringing to consciousness through reflexive activity that I can attempt to "bracket" off this material (Beyer, 2016). I locate myself, as author, epistemologically and ontologically within a critical realist/contextualist position, and acknowledge that the research will inevitably have limitations based on the relative success of the study in remaining true to the underlying, intended approach of the work.

#### **Analysis**

The author, as a first-time IPA researcher, chose to manually analyse the transcripts to allow for complete "immersion" in the data, and to ensure that the stages of analysis as described by Smith, Flowers & Larkin (2009) were followed to facilitate the production of a sufficiently interpretative account. Individual accounts were analysed using a multi-step approach where the verbatim transcript was generated by listening multiple times to the recordings, supported by field notes made at the time of interview and immediately afterwards. The researcher transcribed and corrected over several versions, comparing the written transcripts to what was spoken to check for accuracy, and as useful adding notes about non-verbal communications, such as tone of voice, intonation, emphasis, breathing, pacing and so on. In addition, notes were made throughout analysis about the researcher's own experiences of the analytic process, something which enabled her to recognise the challenges of the transcription process and the dynamic, almost organic process of

moving from transcription to themes. The transcripts were read multiple times and initial notes made alongside, some of which were gradually transformed into emergent themes, and relationships between themes were sought to enable clustering of related concepts. At individual participant level, this clustering was carried out and was also mapped visually by the researcher on to a large sheet of paper, cut out, and physically rearranged into different clusters to "play" with the spatial and temporal aspects of the accounts. This type of creative approach to the analytic phase is encouraged by Smith et al (2009) because they argue physically moving away from the accounts can support the process of "abstraction" and development of higher order themes. The analysis then progressed in this vein and shifted back and forth between stages, and between participants, until the final accounts were completed.

The analytic process was immersive and complex in that there was both a deep engagement with the participants' accounts and sense-making combined with the researcher's own active sense-making. In time, super-ordinate and sub-ordinate themes were identified that encompassed all participants. Finally, as the analysis from these stages and cases was brought together, an interpretative account was worked up situated within the relevant psychological theoretical frameworks. Finally, an interpretative *and* phenomenological account was produced which balanced the idiographic with the hermeneutic aspects of good IPA research (Smith, Flowers & Larkin, 2009) contextualised to the particular socio-cultural context in which the interviews were situated.

# Quality

In determining how to assess the quality of this work, careful consideration was given to reflecting on the extent to which known ways of evaluating qualitative research were compatible with the aims of IPA. Assessing quality in qualitative methods is controversial, not least because the idea of set "checklists" runs counter to more constructivist or contextualist assumptions. Related to this, attempts to bring qualitative research into "evidence-based" practice and policy-making, has arguably resulted in mixed methodological approaches that can lack internal validity due to epistemological incoherence (Harper, 2008). For example, the use of "interrater reliability" lacks validity itself as a quality assessment tool (in qualitative research) because it contradicts the very notion of subjectivity, and at best, Yardley (2000) argues, would be an agreement about an interpretation. Similarly, triangulation (Lincoln & Guba (1985), cited in Braun & Clarke, 2013) is based on using different methods to cross-verify interpretations based on the assumption that if two different approaches lead to the same outcome then there can be more confidence in the validity of that outcome. However, this premise makes little sense if we accept, within a contextualist empiricism, that multiple perspectives must by definition produce varying types of knowledge and understandings, and that no one knowledge is the "right" one. Moreover, for the present study, it was an important part of the research aim to attempt to provide insider accounts within an interpretative method; to add yet more layers to the interpretative phase risks moving beyond the "double-hermeneutic" to the triple or beyond. Yardley (2000) herself has argued similarly that the broad issue of subjectivity and its relation to validity extends into methodological pluralism, where imposing hierarchies of interpretation over varying approaches would privilege certain types of knowledge, and with it certain voices over others (and most likely subjugate first-hand accounts).

However, to resolve the underlying dilemma that of how to demonstrate validity if we reject all forms of quality assessment (and wish for qualitative methods to expand their sphere of influence within wider policy-making) Yardley argues for a set of four flexible "suggested criteria" (2000, p.219): Sensitivity to context; commitment and rigour, transparency and coherence; and impact and importance; and these have been applied flexibly (as she advises) according to the particular needs of the method used, and combined with Smith's (2011) later IPA-specific guidelines. For example, a reflexive diary was used particularly at interview stage and during analysis to provide a way to demonstrate personal thought-processes at these key points. The following excerpt provides an example of the active reflection and reflexive self-awareness that the researcher attempted to engage with as a core part of the research experience:

"A supervisor recently reminded me that we can only work with what information we are given by clients, and I've begun to think about the story I would (choose to) tell if I were mentally unwell and meeting with a therapist. Would I use an element of performance to construct an acceptable version of myself? Or would I simply be trying to help someone else understand so that together we could try and work out where to go? What might this mean for my research study - will I reproduce accounts that because they are after the event, as it were, be too self-aware to get close to the "real" experience; or is their own secondary sense-making going to be just as, or even more, real than that which was experienced in the moment? I suppose there is no easy answer, and therapeutically at least I have to respect the story I am given to work with. Recognising these thoughts though helps me to make sense of why I am drawn to qualitative approaches, particularly IPA; that struggle to find meaning in experience is so central to what it is to be a person,

and IPA allows me to feel a sense of internal consistency between my clinical practice, my research and my personal philosophy."

Such preoccupations are a reality of research, and the use of a diary to note these reflections was helpful because it brought to consciousness, much like supervisory discussion, issues that if not voiced could influence the research in such a way as to be outside of critical awareness. In addition, to maintain a transparent connection from the earliest stages of the project to final write up, all versions of documentation from draft proposal stage through to final write up were kept. Therefore, for "audit" purposes, the development of the study from beginning to end was evidenced, and added another element of quality control. Furthermore, the researcher attended an IPA training workshop, run by a leading IPA researcher (Dr Michael Larkin, University of Birmingham) prior to beginning the active stage of the research, to support her own understanding of IPA as an approach. The transparency and coherence of the final report may also be judged by the degree of clarity with which the research process is described, and drafts have been provided for supervisory discussion. Furthermore, the supervisory process itself adds another important way to check the plausibility of the interpretative account, not agreement between interpreters, but to ensure that the final account is based in the original data. For example, throughout the analytic process, transcripts were brought to supervision and as a group of researchers, we examined these and discussed initial coding and emergent themes. This was particularly helpful where differences in perspective brought about by different professional orientations impacted on collective sense-making. For instance, a more sociological perspective might consider issues of power or agency in relation to a social disability model of mental health, compared to a focus on relationship and attachments from a psychological

perspective. While discussion did not necessarily change these interpretations, the supervisory context enabled a collective awareness-raising which provided a useful quality check for the plausibility of emerging themes.

Finally, the impact and importance of the research will be reflected by its usefulness and be interesting to read, telling the reader something new and illuminating about the subject matter (Smith, Flowers and Larkin, 2009, pp. 181-2). A discussion of the relative success of the study is presented in the Discussion and Critical Evaluation.

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# **Discussion and Critical Evaluation**

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#### **Discussion and Critical Evaluation**

The aim of this discussion and critical evaluation is to place the findings of the research study within the context of the relevant literature, including the narrative review presented alongside the current study. This will allow the thesis as a whole to be located in terms of how it complements or contrasts current understandings of the service user perspective in peer support (PS).

Next, wider clinical and service development implications, and suggestions for future research are presented. This is followed by a critical appraisal of the strengths and limitations of the research, along with a reflexive consideration of the methodological decisions made.

Finally, an account of the author's own critical reflections is presented to provide the reader with an appreciation of the subjective context of the study and includes excerpts of the reflexive journal maintained during the study.

# **Findings and their Theoretical Implications**

Firstly, the central importance of relationship to service users' positive experiences of PS was identified in the review ("The Centrality of Relationship"), and in the present study. Service users felt safe, trusted their PSW and saw them as credible due to their lived experience. A secure relational foundation appeared to function as a necessary basis from which the active work of recovery could take place, and therefore preceded what Gillard et al. (2015) referred to as later process outcomes, which in turn preceded operationalised recovery outcomes, such as increased social functioning.

The present study confirmed these findings, with participants emphasising both practical and experiential elements of the relationship. Practical help was equally valued and appeared to facilitate early relational bonding because it provided proof of commitment, a finding similar to that of the Davidson et al. (2001).

The phenomenological focus of the present study brought attention to the experiential elements of service user experience in relation to the PS relationship. Participants' sense-making was sometimes complex as they reflected on the somatically experienced moments which signified to them that their connection with the PS was a positive experience, including 'warmth' and 'relaxation'. These feelings appeared to arise from an emerging awareness that this helping relationship would perhaps be different to those they had previously encountered. The findings also support the notion that the minutiae of social communication form an important part of what makes successful PS, and therefore the importance of relationship should not be overlooked as models of PS are developed. In particular the importance of empathy and a secure relational base, it is argued are necessary components of successful PS.

Participants all spoke of the central importance of their peer support worker's (PSW) lived experience as providing a foundation for the relationship. The impact of lived experience began immediately upon having the role explained, and while most wanted to hear their PSW's story, the amount of detail needed varied. As a result of disclosure (tacit or overt), participants reported a sense of trust and being at ease with their PSW. With reference to the wider literature consumers previously reported in a qualitative study a sense of emotional connection with their PSW, which they attributed to lived experience (Coatsworth-Puspoky, Forchuk, & Ward-

Griffin, 2006). In the present study, disclosure was experienced as normalising, and bringing a sense of "permission to talk [about their mental health]", which for some was described as a sense of relief. In the review, Gidugu et al. (2015) also reported that sharing of lived experience was associated with service user reports of normalisation, and of improved self-esteem. None of the participants in the present study reported negative experience of hearing their PSW's story, and indeed many found it transformative, in contrast to Wrobleski et al. (2015) in the review, in which some participants reported distress at hearing their partner's lived experience. The present study did indicate however, that there is variability in participants' relative desire to know detail, suggesting that for some just knowing the PSW has lived experience may be sufficient, while others may appreciate similarity of experience and wish to know more. These findings support the inclusion of clinical supervision structures within PS programmes, to support the skilful interpersonal communication needed for safe and therapeutically useful disclosure, and to support PSW to be reflective and have awareness of how much or what they feel able to share. Moreover, the accounts in the present study suggested that disclosure also acted as an 'invitation to be' with their PSW resulting in participants feeling 'less alone' with their experience. This brought a sense of hope that recovery might, after all, be possible. This invitation to belong implies a sense of social connection, and with it the possibility of group membership. Indeed, participants spoke of their sense of admiration and internal sense of change as their beliefs were challenged about what may be possible for them in terms of their recovery.

There is little reported in the PS literature about the process of disclosure.

The present study adds to current understanding because it suggests that while disclosure as a phenomenon will vary in content, style and timing, there may be

specific qualitative indicators linked with a positive experience. For instance a calm and emotionally contained disclosure appeared to be experienced as useful by service users because it maintained the shared focus on their needs. Relevance was also valued, not in content but in terms of the emotional experience of having had mental health difficulties and of being a "mental health patient", including feelings of "worthlessness" and "despair". Further, participants reported that they felt heard and truly understood because their PSW had "been in their shoes". There was a palpable sense of relief at not having to explain what it felt like to have mental health symptoms and this was contrasted with experiences of non-peer professional help where disclosure was encouraged and yet was not uniformly experienced as helpful when it felt burdensome, tiring and reinforcing of their sense of difference. This suggests that while disclosure can act to equalise power imbalance, in certain contexts it can serve to further reinforce feelings of isolation and powerlessness, and as a finding speaks to Marino, Child and Campbell-Krasinki's (2006) description of disclosure as a "complex process invested in power".

By focussing on the phenomenological aspect of the service user experience of peer support, the present study provides a novel insight into the earlier phases of the peer support relationship and the potential impact of disclosure and lived experience as a key factor in establishing relationships. These early experiences suggest that non-verbal, social communicative moments in which empathy and a sense of being understood and heard are also important building blocks of relationship. The experiential focus of these findings indicate that the positive emotional impact of lived experience and disclosure may be experienced at a profound level, but is often not necessarily easily verbalised. Noticing positive affect and building on such feelings by bringing them into awareness, through shared talk,

may be another way in which PSW can help to build hope with service users and effect therapeutic change, and such an interpretation situates these findings beyond current peer support literature. For instance, Myers (2000) discusses the phenomenon of intuiting a partner's experience within the context of experiences of being therapeutically heard, and distinguishes between intellectual, sympathetic understandings and felt, empathic experience of another's emotional state: a direct knowing rather than a reflective, intellectual process of sense-making.

A further finding within this theme was the sense of relational safety within the PS relationship, and related to the review theme of "managing boundaries". Participants spoke of a sense of 'heldness' and emotional containment that appeared in large part to be established through the sharing of lived experience, but importantly maintained and developed through consistent boundary management. PSWs were neither a friend nor were they like a mental health professional, instead they inhabited a space midway between. In making sense of this, participants related their felt sense of safety with a trust in their PSW and that certain lines would not be crossed by for instance being invited out in between sessions. In addition peer support workers demonstrated some flexibility in communication style, including use of humour but not inappropriately, and went "beyond, but not too far' in offering help spontaneously which was experienced as thoughtful and added to service users' sense that they were deeply known and understood by their PSW. The issue of boundaries in the peer support literature is longstanding, and studies of the PSW perspective suggest that confusion can exist in how best to maintain the right balance between friendship and professional accountability (Mowbray et al., 1998). In Repper and Carter's (2011) review of the PS literature, they suggest that the intermediate position of the PSW role between representative of the mental health

team on one hand and supportive therapeutic friend on the other means that clear guidelines for training programmes were needed, but acknowledged that until the processes involved in disclosure, for instance, were better understood, this would continue to present challenges.

Interestingly, in the current narrative synthesis, Cabral, Strother, Muhr, Sefton, & Savageau (2014) suggest that issues of boundary confusion were more of a concern to PSWs than to service users, who actively welcomed boundary flexibility because they equated it with a sense of relational equality. Similarly, participants in the present study spoke of a sense of equality arising out of the less formal style of interaction and did not report boundary confusion. However, our findings did suggest that rather like disclosure, boundary management may be best understood as a product of the negotiation that occurs both tacitly and explicitly in successful PS relationships. This suggests that training programmes should include discussion of the importance of individualising boundaries within limits, the use of candour in communication, and that both PSW and service user should be encouraged to develop awareness of their own "safe limits".

Participants in our study valued the use of non-medicalised language because of its communicative power and its equalising effect on relationship dynamics. The use of medical language with some non-peer professional interactions was reported as a barrier to relationship, and participants described a sense that such encounters often felt driven by an agenda of information gathering and assessment of symptoms and risk. One outcome of this type of interaction that was counter-therapeutic was that participants' spoke of wanting to "protect" their professional from realising that the interaction was not helpful. This and other reported experiences within the study

suggested that service users, even when very unwell, are keenly aware of the stress that some mental health practitioners are under. By contrast, participant accounts of interaction with their PSW were characterised by a sense of relaxation, and of being listened to. These interactions were also experienced as collaborative, which for participants meant a chance to talk about everyday subjects such as sharing of good news as well as periods of sustained shared focus on addressing difficult issues that needed addressing. Collaborative conversations of the type described by the participants tend to have a mutually agreed focus and are at a pace that allows for both parties to pause and reflect and, as necessary, to recover emotional equilibrium. This kind of intersubjective 'dance' is well established as a vital ingredient present in secure relational bonds (Trevarthen & Aitken, 2001). The quality of interactions described in the present study supports a theoretical model of PS with quality of relationship, and the contributing elements of disclosure and flexibility of boundary as possible 'critical ingredients' of PS. Indeed, within the broader adult attachment literature, it is accepted that adults will seek out so-called attachment relationships during times of vulnerability and illness, or relationships in which they can receive nurture and care (Bowlby, 1988). Further, effective therapeutic interactions have been suggested as based within the felt response of "being present" with another (Slade, 1999). The so-called "secure base" (Bowlby, 1988) builds confidence in the patient's ability to explore beyond their comfort zone and tackle the difficult issues that they may have not felt able to do on their own. The successful examples of PS relationships within the present study suggest that security of attachment is indeed important in this context.

Secondly, participants in the current study, spoke of the benefit of having a 'representative' who could liaise with the mental health team, accompany them to

appointments and ensure that tasks were actioned. Gidugu et al. (2015) and Gillard et al. (2015) in the review also found that service users appreciated their PSW acting as an advocate to the mental health team. This was particularly helpful where service users anticipated poor interactions with health professionals based on previous experiences or expectations of stigmatised attitudes. While our findings did not suggest that the mental health teams in this study held these attitudes, the participants did admit to being more likely to attend appointments with new professionals than if they had been alone explaining that their symptoms sometimes made engagement difficult. However, they also spoke of mental health teams not returning their phone calls, cancelling appointments without explanation, and high turnover which together had undermined the formation or maintenance of effective professional-service user relationships. This finding suggests an understanding of 'engagement' as a two-way process, rather than something service users alone are responsible for. In circumstances where relationships were yet to establish, or where service users anticipated negative interactions based on previous experience, the PSW was able to act as a "bridge" and supported the relationship from both sides. Over time, participants spoke of how their relationship with their mental health team had improved and made sense of this as due to being less unwell and that their PSW had maintained the relationship with the team for them until they were more able to do so themselves. This finding is consistent with Gillard et al. (2015) that the trust built between PSW and service users extends in time to the mental health team. The finding is also consistent with the wider literature on patient-professional relations in which client characteristics (e.g., a loss of autonomy and identity as a result of mental illness) interact with service factors (long waiting lists) and relational factors (poor therapeutic alliance and not feeling listened to) to generate poor engagement

(Priebe et al. 2005). This suggests that services could benefit from an increased awareness of the likelihood of such factors impacting negatively on engagement and proactively referring some service users to PSWs to help mitigate such difficulties. This finding supports the notion that training for PSWs might incorporate some of this advocacy role but with a view to modelling and scaffolding the service user's development of the ability to self-advocate where this is a difficulty.

Thirdly, the practical support offered by PSW in their advocacy role, was mirrored by a focus on practical change during sessions with the participants. Of particular value was a sustained focus on agreed goals across multiple sessions and a determination held by the PSW not to allow difficult issues to be avoided. In addition, talk during sessions tended to be reflective and PSWs helped the participants to notice change, both through their talk but also by encouraging the recording of achievement, which kept a generally positive tone to sessions and provided motivation to tackle difficult issues. Conversely, participants also spoke of the sensitivity of their PSWs in recognising genuinely difficult times and knowing when not to pursue goal-directed activity; a finding which relates to the Vygotskyan concept of the zone of proximal development (as cited in Kilgore, 1999), in which the 'teacher' is sensitive to what the 'learner' can or cannot do without help, and if they can make use of that help in that moment. Judicially backing off from goaldirected activity at these times helped to maintain trust, a collaborative sense, and the service user's sense of agency whilst at other times service users felt that their ambivalence might be more likely to benefit from being gently challenged. The difficulties that the participants spoke of in deciding if they felt able to engage with goal-directed work that for them brought with it some element of psychological threat (e.g., exposure work for anxiety), were typical of the ambivalence often

experienced by clients when they simultaneously wish to approach and avoid tasks designed to help them overcome fears. Participants reported having progressed further in this type of work with the support of their PSW than they had previously done with other forms of help, such as cognitive behavioural therapists or psychologists.

This positive result appeared to stem from their secure attachment as previously discussed, but also because sessions were often carried out at home where problems frequently occurred, and these could be tackled more directly and the work could be done together. In addition, PSWs appeared to be know when to push them and when not to, and participants spoke of their PSW's ability to motivate them to action through recognising their fear or ambivalence but reminding them that their avoidance ran counter to achieving their ultimate goal. Moreover, their accounts suggested a sense of hope arising out of their relationship with their PSW and the shared focus and commitment to change.

These findings suggest that the PSWs in this study were able to achieve a greater level of change with the participants because their approach was patient-centred, they chose goals which were meaningful to the participants because they could work on them *in situ*, and were able to resolve ambivalence and build *intrinsic* motivation because they had a relationship with the participants that was based on trust and a genuine sense of warmth and positive regard. The PSWs were able to 'roll with refusal' on bad days but equally were able to remind participants of the pros and cons of inaction in moments where their sense of connection with the participant suggested that there was room for movement. This approach appeared to provide an effective combination in achieving a better subjective sense of success for

the participants compared to their previous therapeutic encounters. These findings from the current study add to those presented in the review and suggest that in terms of clinical and organisational understanding of peer support it should be understood as inseparable from its particular social context, and that because it can result in increased self-efficacy it can be a stand-alone intervention in its own right or act as a pre-therapy for further therapeutic input.

In the present study, as participants reflected on their progress, they spoke of an increased sense of psychological distance from their symptoms, which cooccurred with their increased desire to re-connect socially. This process itself appeared to have arisen out of the socialisation experienced within the peer support relationship which offered a space within which they could contemplate and practice identities counter to that of 'mental health patient'. Participants spoke of a sense of having travelled a distance in time from how they were when unwell and in the lead up to mental illness, and while recognising the extreme difficulty of what they had experienced they also recognised that they had found something positive out of it, namely a new identity and a sense of connection both emotionally and physically with others, and that they, like their PSWs, could use their lived experience of illness and on-going recovery, as a force for good. This sense of intrapersonal growth out of what had been a traumatic experience was a way for them to make sense of these difficult experiences, and suggested that the phenomenon of empathy had in effect accompanied them throughout their peer support journey, changing from something offered by another, to something experienced internally and finally to something that they were then able to offer back out to others as their social connectedness and wellness increased.

Recent qualitative studies of peer support, described in the accompanying review, identified role modelling as an important contributory factor underlying participants' improved mental wellbeing. For example, Salyers et al. (2009) suggested that service users engage in internal imaginative processes in which they contemplate positive futures as a result of the role-modelling and normalisation experienced within the PS relationship. Similarly, Gillard et al. (2015) also reported improvements in individual mental wellbeing and linked these outcomes with rolemodelling, normalisation and de-stigmatisation in their model of PS. The third theme of the present study was compatible with this model, but also provides an indication of the possible internal change that may precede more observable outcomes associated with mental wellbeing and recovery, such as improved social connectedness. For example, participants spoke of an emerging understanding of symptoms as transient and less functionally incapacitating, and were able to recruit self-help strategies learned with their PSW, or ask for help where previously they would have kept their experience secret. This resulted in an increased sense of being able to 'do despite'. These changes appeared to come about as a result of a combination of effects of the PS relationship, including role modelling, how to selfmanage, and the promotion of a sense of belonging, positive identification and a sense of optimism.

This change in perspective mirrored a reduction in participants' sense of internalised stigma as was evidenced by their increased ability to talk about their experiences with others. This appeared to come about, at least in part, because they identified positively with their PSW, who by being competent and professional demonstrated that mental illness could be an asset rather than an impediment to a positive self-identity. Then, over time as their confidence grew they began to seek

out similar others through the social network provided by their connection with their PSW. This suggests that the positive identification that begins with their PSW extends to include others and supports the development of an expanding social network, thus reducing isolation.

Such an interpretation locates these findings within the broader social psychological literature of social identity and group membership (e.g., Tajfel & Turner, 1979, cited in Austin & Worchel, 1989) and social comparison (Festinger, 1954) because the sharing of experiences previously hidden due to stigma and shame offers social connection and membership of a group, turning a stigmatised experience into an asset. Being with others who may be further along in their recovery, and so can share their knowledge as well as their experiences, has been previously suggested as one way in which PS may engender a sense of hope (Repper & Carter, 2011).

Alongside the above changes, participants in the present study spoke of an increased sense of understanding, empathy and compassion towards others experiencing similar difficulties. This change also appeared to arise out of the social connection offered in the PS relationship and manifested itself in a desire to contribute and use their experiences as a way to take up occupational roles or family roles that they had lost or only partly been able to maintain. Within this, there was an articulated movement away from a sense of self dominated by being a patient, and being 'done to', towards a richer, more varied sense of self, in which multiple roles or behaviours were now possible (parent, employed person, friend), including a sense of being more in control over one's own recovery. This finding is consistent with the broader literature on the impact of illness identity on mental health

recovery, in which identity in this context reflects the combination of an individual's own understanding of illness (i.e. 'survivor' or 'patient') with wider social understandings of for instance, what it means to have mental illness (Yanos, Roe & Lysaker, 2010). In the context of the current study, such an interpretation suggests that by working with a PSW, internalised negative stereotypes which contribute to self-concept may be challenged and replaced with more positive and empowered understandings. The impact of how a person makes sense of mental illness and recovery may therefore be an important contributing part of models of PS if it can support recovery by moving a person from self-understandings dominated by a sense of helplessness or incompetence (Yanos et al., 2010) towards empowered identities associated with a sense of "hope, control and opportunity" (Repper & Carter, 2011).

# **Clinical and Service Implications**

PS has the potential to bridge the divide between service users and mental health teams where there is a history of negative experience, or when an individual's self-confidence and/or limited opportunities for social contact makes successful engagement unlikely. These findings alone suggest that PS services should continue to be integrated within mental health services: Providing increased choice of intervention to service users, including PS, may make a genuine difference and improvement to service user experience and outcomes.

However, PS has some unique qualities that could come under threat if services do not understand what these qualities are, why they help and how to protect them from being diluted by the misapprehension that difference may represent a threat or undermine other more traditional interventions. For example, flexibility of boundary gave rise to positive emotional benefits of inter-subjective warmth,

empathy and understanding. This flexibility took the form of use of everyday language, a highly collaborative approach, a sustained practical focus, and by skilful interpersonal connection that was experienced as genuine, accepting and generous. There was no evidence of unethical practice such as participants reporting a sense of boundary violation; indeed as service users they valued the professionalism of their PSW, but simultaneously experienced a sense of 'being" rather than just 'doing", which had characterised some of their encounters with non-peer professionals. Moreover, this study suggests that PS is valued by those who use it, and that they appreciate it for its difference and ability to complement existing non-peer support. Therefore, from a service perspective, the inclusion of PS as an available intervention is consistent with current mental health policy, in which service user choice and involvement in designing and running services is seen as a core part of the move towards recovery-based services (Department of Health, 2012).

Pressure to evaluate PS, however, is an inevitable consequence of services that are measured on specific service criteria. This need not be a problem for PS programmes, but this study emphasises that evaluation methods used should include elements of subjective, intra-personal change as well as later, operationalised "downstream process outcomes" (Gillard et al., 2015). Based on the findings of this study, examples of some potentially useful targets of evaluation could include measures of self-esteem, for example, Rosenberg's Self-Esteem Scale (Rosenberg, 1965) and measures of self-stigmatising attitudes such as the Internalised Stigma of Mental Illness Scale, (Corrigan et al., 2012), since the processes of normalisation and role modelling that occur during PS may impact on these constructs. Clearly further research is needed to extend these findings and to test to what extent such measures would provide a meaningful fit with emerging models of PS.

Finally, staff awareness of both recovery and PS is important not least because the intermediary function of PSW may mean that they find themselves on occasion in situations of disagreement with non-peer colleagues. If PSW support structures are inadequate, they may experience burnout if their mental health symptoms reoccur. Negative attitudes to PSWs may reflect underlying beliefs about the potential of seriously unwell individuals to recover, and scepticism about the value of consumer-led initiatives. Education sessions and information posters could be a simple way to ensure a good level of mutual support between PSWs and mental health teams, and could encourage wider de-stigmatisation of mental illness through supporting health professionals to consider the impact of their own mental wellbeing on service delivery.

## **Strengths and Limitations**

The study has demonstrated the value of using a qualitative, idiographic approach to the exploration of a relatively under-studied phenomenon, and in doing so has provided a means through which the experiences of those receiving PS can contribute to our understanding of the mechanism of PS. The use of Interpretative Phenomenological Analysis (IPA, Smith, Flowers and Osborne, 2009) has enabled a depth of analysis with a small sample that would not have been possible with a less idiographic or quantitative approach. In addition, IPA actively seeks to go beyond description to place the participant's own sense-making within a framework of psychological theory that they would not have accessed directly in their accounts. However, IPA does present a challenge for novice researchers, because 'good' IPA (Smith, 2011) has to balance the intellectual demands of second-order interpretation with the commitment to the idiographic and the phenomenological. However, the

committed use of active research supervision during this study has supported the quality of this study and its findings, through the use of active reflection and checking for the plausibility of findings and their transparent connection back to the original data. The sense-making of the participants' own interpretations is also not neutral and is informed by earlier experiences of research, knowledge of psychology, and of life more broadly. Nonetheless, the findings of this study do reflect a considered and rigorous approach and all interpretations are grounded solidly in the participants' accounts, and have been checked for plausibility, interest and theoretical contribution throughout.

The contextualist stance of IPA reflects my own position. While I have attempted to "bring to consciousness" my pre-understandings (fore-knowledge, experience, bias and values) through supervisory and peer supervision, and through the use of a reflexive journal to note my thoughts, ideas and decision-making, these are not intended to result in the production of a final, 'correct' outcome. Rather, this has produced an outcome amongst other possible outcomes, but one that reflects, I hope, some of the complexity and contradictions of individual experience. The following excerpt gives a sense of the decision-making process experienced in the early stages of this study after having presented my early ideas for the study to my fellow students and academic tutors. I have included it here to provide an insight into how the use of a reflexive journal brings the researcher's subjectivity into the research process, and in doing so stimulates a 'bringing to awareness' of one's own pre-understandings:

"Some of the comments following on from presenting our research proposals to the cohort and tutors made me think more about why I've chosen to use IPA. I am aware that it is not a neutral choice because it reflects something of me, as someone who often feels slightly out of time with her cohort as an older student, a career changer, and a parent. Choosing a qualitative project feels like a statement of intent that I want to sit slightly outside and look in. I wonder if it also feels like a good fit for me because it will allow me to focus on individual accounts while making links with wider theory; I enjoy doing this and it reflects my emerging practice in general in terms of my preference for thinking widely around a person's difficulties. Finally, there's a sense of returning to unfinished business - my undergraduate attempts at qualitative research and IPA were so enjoyable but felt very unfinished. Using IPA now, years later and in this context, in mental health research, seems very appropriate given that mental illness itself is, in my mind, also inseparable from context and from the struggle to make sense of experience."

I was aware at this stage in the working up of the proposal for the study that I could use an alternative analytical technique such as thematic analysis. However, I felt it was important to maintain an idiographic focus and also to attend to the experiential; something that I value in my own clinical work as I support clients to make sense of their own experience through a focus on process and collaborative sense-making to facilitate them to find their own way through their difficulties. I was unconvinced that if I were to choose thematic analysis for my analytic method that I could maintain a sense of epistemological coherence in relation to my own contextualist position. Moreover, I was attracted to the existence of a well-established framework in IPA, which I believed would support the production of quality work, given my relative inexperience. These issues are further detailed in the Extended Methodology chapter, but in relation to the current discussion, the choice of IPA is, I believe, a

strength of the current study and has facilitated an output that has managed to attend to often-overlooked individual experience while situating that within a wider psychological framework, and in doing so contribute to wider PS research.

Nonetheless, the study has several limitations. Firstly, it could be argued that it has suffered from unintentionally selective sampling resulting in an overwhelmingly positive impression of PS. In retrospect, the decision to access potential participants through their PSWs may have inadvertently introduced bias, although equally, there was a pragmatic need to design a workable recruitment strategy that would also meet all ethical standards. There was also an attempt to generate a sample that was homogenous in line with guidelines for IPA (Smith et al., 2009), and the inclusion criteria helped to support this. However, given the time constraints of this project an element of opportunity sampling arose and two participants had recently begun a PSW training course, further supporting the assertion of positive bias towards peer support within the sample. If there had been a longer period of time available for recruitment, it is possible that a larger number of potential participants might have been identified and a less opportunistic recruitment could have taken place. On the other hand, I was acutely aware of the generosity of the individuals who offered their time to participate, and recognised my own ethical responsibility to the participants to facilitate their involvement in the study. A pragmatic solution to the problems of recruitment described above, could have been to have used some additional data collection methods in addition to interview, such as diaries used to record impressions of PS immediately after participants completed sessions with their PSW, and/or anonymous surveys with free-text options, and it is unfortunate that this opportunity was missed, especially given the identification of positive bias in the research included in the systematic review. Methods such as

these would be a simple way to improve PS research in the future but need to be considered upfront during the design phase and included within ethics applications.

A further limitation is that because the study was carried out in one area of the UK, and within one NHS Trust, that experiences of PS may be different in diverse contexts, and also because all participants described themselves as "white, British", service users from different backgrounds, and different parts of the UK, may have different experiences. Despite these reservations, the findings of the study can be argued to be representative of service user experience, in similar contexts, when PS *works well*. In addition, the study has, to my knowledge, provided novel insights about the importance of social communication, empathy, advocacy and psychological change that occurs for service users receiving PS.

#### **Further research**

The study could be extended and improved by exploring the impact of PS on individuals as they contemplate, practice and transition to wellness identities, and in parallel how PSW and service user negotiate the end of their relationship. A mixed-methods approach could be used to further explore the changing narratives around identity during peer-supported recovery, and the possible associations between different identified psychological constructs, such as internalised stigmatising attitudes to mental health with changes in self-esteem. These findings suggest that future research should not overlook the importance of such subjective, internal outcomes, because they posit a model of PS in which these may constitute early indicators of change that could precede and contribute to later observable changes, such as social or occupational functioning. If service evaluations focus only on the latter in attempting to measure the effectiveness of PS, they may fail to reflect the

full process of change that service users go through and in doing so, may inadvertently assume that a lack of change at the social level reflects a lack of internal change.

#### Conclusion

The present study provides a complementary perspective to the existing PS literature due to its phenomenological focus on the service user experience. Taking this perspective has provided evidence of how successful PS is experienced by recipients, and that disclosure of lived experience is linked with experiential moments described variously as warmth, a 'rising up', a sense of hopefulness, associated with the normalisation of mental illness that may impact positively on subjective and objective elements of identity. Therefore, with reference to the Gillard et al. (2015) change model of peer support, the present findings appear to be consistent with their conclusions, but also support the addition of internal, experiential processes that may be associated with early change. The addition of the psychological and emotional processes of successful peer support could be included in developing models because they represent key aspects of service user experience and may precede outcomes possibly more amenable to measurement. In addition, it has been suggested that hope and associated positive affect appeared to emerge spontaneously out of the interpersonal exchanges of PS underpinned by disclosure of lived experience that was personalised to each pair. Hope then appeared to be maintained possibly through supported socialisation, and shared learned behaviours such as the sustained focus on positive change. These emotional and practical elements together were particularly welcomed by the participants.

Just as the process of disclosure was flexible and personalised, so too was the understanding of boundary. Our findings also suggested that the quality of relationship was characterised by skills of empathy, warmth and acceptance; akin to the so-called "core conditions" of successful therapeutic relationships (Rogers, 1957). Indeed, in Repper and Perkin's (2003) model of social recovery, they argue for interventions that are based on quality relational contexts built on an awareness of the importance of power, vulnerability, exposure, dignity and respect. The positive experiences of PS in the present study suggest that when it works well, PS is an intervention which fulfils such criteria.

Further research is needed to explore the subjective emotional and psychological effects of PS because, as has been suggested, to do so supports a conceptualisation of PS that reflects the experiences of its recipients, rather than the priorities of mental health NHS trusts. Recognising the subjective and the intrasubjective is important because by noticing them within the peer support relationship they can be brought to awareness, and may provide a basis from which further, additive change occurs. Recovery is after all a subjective and personal phenomenon that occurs within a social context, and models of PS need to be able to incorporate all elements of this complexity.

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# Appendices

**Appendix A**. Quality appraisal of selected articles and CASP scores

	10.	9.	œ	7.	6.	,s	<del>4</del> .	ω	.5	:-	0
Total CASP score	). Research value?	Clear statement of findings?	Rigorous data analysis?	Ethical issues considered?	Researcher-participant relationship considered?	Appropriate data collection method?	Appropriate recruitment strategy?	Appropriate research design?	Qualitative methodology appropriate?	Clear statement of aims?	CASP criteria
16	1	2	2	2	_	2	1	_	2	2	Gidugu et al. (2015)
20	2	2	2	2	2	2	2	2	2	2	Gillard et al. (2015)
17	2	2	2	2	1	1	2	1	2	2	Cabral et al (2014)
18	1	2	2	2	2	2	1	2	2	2	Wrobleski et al. (2015)
13	1	2	1	2	0	1	1	1	2	2	Lawn et al. (2008)
16	1	2	1	2	2	1	1	2	2	2	Henderson et al. (2008)
17	2	2	1	1	1	2	2	2	2	2	Davidson et al (2001)
10	1	1	0	1	0	1	1	1	2	2	Salyers et al (2009)

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article. Gidugu et al., (2015). (1/8).

United States. "Large, not- for-profit organisation".	Context
Post-Doc with experience as a peer-advocate, trainer and peer support specialist.  Non-peer Senior Researcher.  Non-peer third researcher (consensus/oversight).  No reflexive consideration evidenced.	Researcher characteristics
Service Users N = 19  12 female. 47 yrs old (±12)  47% white, 21% African- American 25% Hispanic 5% Native American	Participant characteristics
Individual Peer- Support.  PSW formally trained.  Employed/Paid.  At least 10 weeks of support received – but varied.	Type of Peer Support
To clarify role ambiguities of PSW, elucidate processes of individual PS, clarify what makes PS effective from point of view of recipient  (Expectations of recipient; nature of the support as perceived by recipient; recipient perceptions of effectiveness.	Research Aims
Qualitative. Semistructured interviews. Analysis method not named but consistent with Thematic analysis.	Method
Practical, instrumental support highly valued  Peer Support reduces isolation through social contact not otherwise available  PSWs are role models, aspirational, and promote move towards self- advocacy  "Core conditions" vital – humanity restored via warmth, empathy, genuineness.  Relatedness mediated by lived experience – normalising improvement to self- esteem  Role boundary issues are of concern to recipients  Service user quotes	Findings
Convenience sample  Variation of amount of PS provided.  Did not explore recipient experiences/ perceptions of differences in relationship between PS and "clinical" relationships Acknowledg ed literature base has moved on since study carried out. No control comparison with non- peer support.	Limitations
Future research to focus on "gaining a better understand ing of the unique contributio n of peer support to recovery from the perspective of the service recipient."	Recomme ndations

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Gidugu et al., (2015). (1/8).

extracts.	Gidugu	et al., (2015)	•		(1/8).			
"Underlined" - Service User quotes;	Mutuality	Links to mutuality via sense of Comfort (Personal Connection) Links to Hope via sharing of LE	Sharing & Identification	- Role modelling  Links to sharing of LE	- Social Support " - Reliability wins trust	Tangible, practical support (show me I can trust you!)	[Engendering a sense of self-]Respect - Emotional support	Key Themes
"Underlined" - Service User quotes; normal text study Author's interpretations; Italics - Reviewer's paraphrase of study Author's interpretations. Bold Italics are Initial emerging synthesising themes.	Mutuality: mutual support. Important to ppts because they felt they were "giving something back" "We just talk, and just share our support. I like to think I'm giving some, too, back.	Sharing & Identification.  Sense of Comfort links to sense of connection and trust: "and shared a little of her story with me. And, umthat was very comfortable.  Umit made it a lot more comfortable to share back. It makes it moremore personal. Notso clinical".	Ppts found the opportunity for mentoring from someone with similar experiences to be the most helpful about peer support.  " the role model mentor, because that's the ultimate example"  Sense of SU able to take on board PSW's advice — their LE has built trust—earned respect—and if she can do it so can I.  Ppt whose PSW did not share to begin with felt "distant" as a result from the PSW—supporting relationship between disclosure and closer relationship)	Gaining confidence in social settings: "before, I wouldn't' talk, I, I get tongue twisted, and I get nervous. But she's helped me to where I don't have to worry or be afraid, anymore.  Opening up new possibilities:new possibilitiesnew opportunities, new things to do, new places to go, and new friends to meet."	Sense of security in the relationship is helped be reliability: "She doesn't work so hard or maybe it's because she has so many caseswhen I'm with PS, it seems like I'm the only person in the world that matters".  Social support - overcoming isolation: "I was at home all the time when I wasn't working, so it was giving me a little outing every monday."	Sense of security in relationship contrasted with Case Managers or other profs—their workload too heavy—"She doesn't work so hard or maybe it's because she has so many cases when I'm with PS, it seems like I'm the only person in the world that matters".  Reliability and the advocacy role improved interactions with Mental Health Professionals—their perceived lack of reliability undermined both self-respect and respect in the MHP:I got some backup, because this guy [Case Manager] wasn't doing nothing she had that find it? Bedding a lack of the MHP:I got some backup, because this guy [Case Manager] wasn't doing nothing she	Respect  Nearly all ppts said they received emotional support: "just someone being there," It's like I had a partner and a friendship! Like a partner I can lean on." "and a lot of people have treated me as let me down and they disparage me he gives me a sense of confidence um., it	Illustrative Quotes to Support Themes

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Gidugu et al., (2015). (1/8, cont.).

xtracts.	Gidu	gu et al.	., (2015)	).		(1/8	3, cont.).			
"Underlined" - Service User quotes:						"Show me"	Boundaries – role/expectation/boundaries Links to expectations	Hope links back to Normalising?	Hope Links to sharing of LE They've done it so maybe I	
"Underlined" - Service User quotes: normal text - study Author's interpretations: Italics - Reviewer's paraphrase of study Author's interpretations. Bold Italics are initial emerging synthesising themes.	Doing more than the "Job spec" seems to be beneficial but managing this and finding the right balance is a challenge. "it made me feel like I had a family. I told her that, I told her, "you're like my doctor, the sister. And I don't feel alone."	situation. Like, right, now, we're going through housing."  Medication support: " seeing what kind of prescriptions I needed and stuffAnd she always made sure, like, I was taking, you know, medications."	off me, where I could focus on other things that were important."  PSW's providing assistance outside of normal duties—driving SU to places outside of scheduled work time, picking up a cheque, spending time looking for housing, giving a ppt clothes: " what I really use him for is to try to get uh, business taken care of with my uh, with my	However, going outside of usual role resulted in SU's feeling emotionally supported as well as the tangible, practical support—"I needed the tangible, and I needed the personal and emotional support, also. And, with her helping me with both of those situations, it took the stress	Perceptions of the scope of PS was confusing for some participants: e.g., Being asked to mediate in a marital conflict. Time boundaries – calling after hours – used text messages after hours to manage boundaries.	Not knowing that PS a service delivered by people with lived experience.  Expectations of instrumental support (paraphrase) – shopping, transportation, and to expand social activities.  Scepticism. Nee ding additional encouragement. Others knew what it was having received it elsewhere.  "Could you please, somebody, give me a job description of what my peer support person can and cannot do."	Boundaries (expectations, role confusion/ambiguity) "I didn't really know what kind of program I was going into when I got there. Yeah, I had no idea what that was" "because I needed something to do instead of staying home all day."	Normalising – not alone, normal, belonged. "them just talking about their experiences was more of a help than I think a lot of than they could imagine". "Cause it made me realise there's other people." "before I met him, um there was only one person that I've ever known that hadmental illness". " there are other people like, uh either like me or going' through the same things".	Hope "And, seeing that she has done itis motivational. She did itif she can do it, I can do it, you know? Ppts who had been in the mental health services for a very long time, when paired with a PSW and hearing their story and seeing where they had got to "I mean, it gives me	

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article Gillard et al., 2015. (2/8)

·	· /	
	peer-led); Partnership (Voluntary: Social services/NHS or Peer- led/NHS); and Statutory (NHS Mental Health Trust) settings.	Context United Kingdom. Voluntary
	Other authors – Clinical health professional (psychologist); Multiple Service- user researchers – role not explicit in article, implied role in analysis and data collection.	Researcher characteristics First author - Health services researcher
	PSW, SU, Colleagues, Managers).	Participant characteristic s  Service users N = 18  (out of a total
	natural variation. Some consumer- operated services and some non-peer led. Mix of paid/non-paid?	Type of Peer Support Not specified. Multiple settings
	grounded model articulating change mechanisms underpirning peer worker interventions.	Research Aims To develop an empirically and theoretically
approach – aware of researcher characteristics/ reflexivity. Inductive, open-ended interview.	worker initiatives. Grounded Theory (Strauss & Corbin, 1998); Constant Comparison process (Green & Thorogood, 2004).	Method  Qualitative case study of 10 peer
engagement with services, strength of social networks Downstream impacts: Recovery Wellbeing Service user quotes	- Role-modelling individual recovery - Bridging and engaging - Emphasises importance of effective peer worker relationship. process outcomes: - Hope, Empowerment, Social functioning. Self-care,	Findings  Identifies: Change mechanisms: Building trusting relationships
Wide range of settings, variation in peer support – this complexity lost in unified approach (reviewer)	mechanisms identified may be more or less valid depending on context.(author)  Modelling may be overly simplistic given complexity of interpersonal relationship and possible range of variables. (author)	Limitations  Broad range of services involved in study may mean that
	Further research to explore relationships between upstream processes, downstream process outcomes and eventual exit outcomes.	Recommenda tions Argues for development of models of change

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Gillard et al., 2015. (2/8)

	Key Themes	Illustrative Quotes to Support Themes
	Building trusting relationships - Making a	Building trusting relationships (Author states this to be primary mechanism underpinning PS interventions)  Author argues data supports this as first step of relationship building – happens due to sharing of lived experience: "it sort of slowly seeped in really that there were people with similar backgrounds and similar histories to mine. I think, at the time, I wasn't aware thatmost of the
	connection	workers had been in hospitalthat was something that came out of conversation, when people sort of made reference to having been in"
	Links to sharing of LE	
	- Building the	"If somebody's coming in and they have self-harmed and if a peer workerhas actually self-harmed in the past they know what that person's coince through so they can actually understand why the vive done it—and how to deal with that nerson—because the vive actually come through
	Links to sharing of LE	it themselves".
	Links to Validation	No service user data presented for this sub-theme. Author interpretation - important for PSW to allow SU to initiate disclosure, rather than
	- Enabling talking	
	and listening Role-modelling individual	and then this starts the disclosure process.
	recovery	enables link to a sense of hone in the fitture. Imagining a new self-identity (author mentions this idea in Discussion) v = can see for
/8)	<ul> <li>Providing hope in</li> </ul>	themselves that the PSW is demonstrating their own recovery - proof in the pudding?) "it buoys you up as well because you know that
(2	the future	these people are able to get on with their lives. And, in my view, it's being of value to your community and to your fellow people and these
		people are. And they've managed to do that even through mental health issues."  Important to SU's that the PSW role is a job – shows to them that being able to work in a caring role because of LE gives a wider
		acknowledgement of the SU's usefulness - powerful symbol of recovery. My mental Illness can be an asset - "it was importantI could
	<ul> <li>Hope held in the</li> </ul>	believewere actually able to be part of an organisation very useful and important"
	work aspect of the	No service user data for this sub-theme: Normalness of the working role—relates to role modelling function, and sharing LE—challenges internalised stioma
	Challenging stigma	" PSW give you the confidence to start doing activities of daily living neonle naturally start backing off from you because they have to
5.	Links to Role modelling.	to let you take more control. But it's at that point you can also start feeling overwhelmed and I think it's then that the PSW would really be
.01	Links to sharing of LE.	able to help, to say, "I understand where you're at. I felt so overwhelmed and this is how I dealt with it." Supported to step outside of
1., 2	CUTION TO SUBSISSION OF COMPT	comfort zone – sense of being alongside – safety-net?  PSWs acting as a bridge between SU and staff "I don't know the personal history of the staff there's that sort of gap that staff have to have
et a	- Supporting self-care,	with service users and I think that's the thing [peer workers], they've been through something themselves and are here and it's benefitted
rd e	functioning	and they get on with the staff" - No service user data for this sub-theme. Trust placed by SU's in PSW was also invested in non-peer
illaı	Engaging with mental	members of the team. Stigma casually or inadvertently expressed by team picked up by SU's, PSW's able to address"the moment you come through the door you know you've got somebody that's going to treat you well because they've been there themselves to some extent, in
G	community –	one form or another. And there isn't that stigma that you sometimes get as well."
acts.		
(tı		

"Underlined" - Service User quotes; normal text - study Author's interpretations; Italics - Reviewer's paraphrase of study Author's interpretations. Bold Italics are initial emerging synthesising themes.

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article Cabral et al., 2015. (3/8)

United Not exp States. Univers health r No con research No reflictionside evidence	Context Res
licitly dity-based escarcher. sumer- ners. exive ration ed.	Researcher characteristics
Service users: N = 10. 50% female. (total N - 68 of SU's, PSWs, & supervisors).  "Receiving peer specialist services in either a residential or supported independent living programme."	Participant characteristics
Not specified although the Peer Specialists had all undergone certified PS training and were spilt into 2 groups recently qualifieds (up to 6 months exp) and experienced (more than 6 months exp.) Implies paid posts?	Type of Peer Support
To explore the client perspective on peer specialists To clarify role ambiguity – and to explore what the role means to different stakeholders to access different perspectives. Aiming for "better utilisation of peer specialists through better understanding.	Research Aims
Qualitative 15-30 minute face- to-face interview.  Consensus coding approach.  Not tape recorded.	Method
Clients descriptions of the PS role are the most concrete; and they are less concerned with role ambiguity than peer specialists themselves  Clients reported lived experience was most important to the relationship.  Lived experience is agreed by clients, peer specialists and supervisors to be the critical ingredient of the PS role.  Themes – unique role within a team (SU quotes); educating others about recovery; role ambiguity; supervisory challenges; positive experiences of SU(SU quotes)	Findings
Data from service users— issues with recruitment relying on PSWs to access— positive bias. Context limited for service users to a residential programme— limited generalisabilit y?	Limitations
PSWs should be seen as part of the workforce – because they address primary care, mental health and social needs.  Role needs clarifying to maximise their effectiveness.  Suggests crosstraining for traditional nonpeer providers on the PS role and education about professional roles for PSW's.  Service user perspectives should be included in broader discussions re recovery.	Recommendatio ns

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Cabral et al., 2015. (3/8)

Key Themes	Illustrative Quotes to Support Themes
Unique role within a team	
(SU quotes);	Most valued element (no quotes)
Advantine to MUT	There is a mutual understanding. We are on [an] equal footing not like the psychiatrist where they are like an authoritative [sic] figure
Advocating to MH I	
-Lived experience as unique	SU perceived PSW as being able to challenge stigma (both external and internalised) through educating mental health professionals in non-peer roles that people with mental illness can be in recovery and work
- challenging stigma	
positive experiences of SU	Clients descriptions of the PS role are the most concrete - not as concerned re boundaries as teams/PSW.
(SU quotes)	She helps me move on to my next stage of recovery. I see her as a person who has reached her goals, but is also human, and things came
Boundary	crashing down on her, but she was able to move on. She is a good role model.
Role modelling	

"Underlined" - Service User quotes; normal text -study Author's interpretations; Italics - Reviewer's paraphrase of study Author's interpretations. Bold Italics are initial emerging synthesising themes.

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article Wrobleski et al, 2015. (4/8)

Canada. Ch Statutory – we Adult ca community mental health and addiction ex services team ref (peer the partnership). in be ou po fav we thi dis sta co pa de ex	Context Re
Clinician researcher working in team where research carried out.  Primary researchers explicitly and reflexively discuss their vested interest in positive outcome because such an outcome had the potential to favourably impact on the PSW program at their worksite. Through this reflexive discussion they state their commitment to keep the analysis focused on participant's descriptions of their experiences.	Researcher characteristics
Service users randomised to PSW arm and interviewed: N=9 (total N of 15)	Participant characteristic s
Employed/ Paid  Formally trained/quali fied.  Individual peer support within a peer partnership – 2 hours per week for 6 months)  Peers employed as PS Ws, and one Peer Coordinator – leadership role.	Type of Peer Support
To develop local knowledge of Canadian peer support, and to increase use of PS within services in Canada.  Specific aims: to compare outcomes (quantitative) and explore perceptions (qualitative) of recipients of peer support compared with non-peer mental health worker.	Research Aims
Randomised, control study. Mixed methods.  Qualitative part: Semistructured exit interview.  Content analysis (Hsieh & Shannon, 2005).	Method
2 main themes – a) Developing a therapeutic alliance (although MHW and PSW experience not clearly separated); and b) managing interpersonal boundaries (e.g., service users not realising they would hear PSWs story)  Service user quotes PSWs produce similar o/comes to non-peers PSWs workers struggle with boundaries.  Is PSW another type of "treatment modality"?  Therefore is the TR what matters more than the "peer" element? – implied reviewers interpretation)	Findings
Two of the four researchers are clinicians working on the team where the research was carried out. "Only 5.4% of eligible participated due to perceived vulnerability of the PS service" flear of negative outcome and loss of service? Reviewers comment)  Mix of MHW and PSW results.	Limitations
Further research required to understand the impact of these changes on PSW clinical practice. Suggests multicentre RCT. Training for PSW to focus on managing boundaries.	Recommendati ons

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Wrobleski et al., 2015 (4/8)

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article. Lawn et al., 2008.. (5/8)

		staff.						
		models of recovery for	and rocus groups.					
	aims.	-Peers as positive role	questionnaires					
	in relation to	notes in the system.	Phone					
	results	support, often filling	with consumers.					
	interpret	of care created by peer	service and work					
	Fails to	-Improved continuum	role (staff),			only on the		
research.			service on their			supports"		
ons for future	limitations	admissions.	impact of PS	agencies.		few other		
recommendati	reflection on	compared with earlier	service; and	other related	and SU	alone with		
No	with no	discharge experience	improve the	service and	hetween PSW	N "living		
	poly pocition	-"vast" improvement in	important to	mental health	normal y	500/ -61-1		
practices).	Overwhelmi		considered	service, other	mutually	condition"		
oriented	carned out.	with the person"	role; any changes	and advice to	support -	one		
recovery-	research was	supports by "walking	of peers in this	sustainability	and emotional	more than		
(towards more	where the	with community	views on the use	development,	instrumental	"several		
change	the team	-Strength of linkage	to consumers;	further	week period -			patient unit.
cultural	working on		perceived benefit	to inform	over a 1-2	diagnoses".		discharge from in-
progress with	clinician	illness,	planning) -	improvement	of 8-12 hours	of		following
necessary to	researcher	experience of mental	(conceived during	about service	peer support	"Full array		immediately
these roles as	Frimary	of their lived	domains	(qualitative)	Packages of	Camera	carried out.	focused
in introducing		and is credible because	determined	feedback	qualified.	hracket	research	Intervention
Sees 'tension''		understands, reassures,	on 4 broad, pre-	<ul> <li>and to gain</li> </ul>	trained and	vr old see	teams where	The state of the s
service staff.	published)	someone who	of feedback based	(quantitative)	Formally	N in 18-25	one of the	health service
systems of	paper not	-The importance of	thematic- analysis	service		25% of total	working in	Statutory mental
test core value	(follow-up		Preliminary	support	hourly)	/5% icmaic.	researcher	
potential to	results.	perspective only:	aspects:	the peer	employment	200/ 0	Academic	
Peer role has	Preliminary	Service user	Qualitative	Evaluation of	Paid (casual	N = 49.	Clinician-	Australia
						K3	3	
HOILS				A IIIS	noddne	CHALACTERIST	characteristic	
Kecommenda tions	Limitations	rindings	Mcthod	Aims	Type of reer	Paruel pant	Researener	Context
Desamanada	T book book on a	Ti allana	Madhad	Danamak	There of Book	Bandalmant	Danamakan	

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Lawn et al., 2008. (5/8)

Key Themes	Illustrative Quotes to Support Themes
	SU felt more trusting of someone who knew what symptoms were actually like, especially psychotic symptoms.
	Appreciated use of non-medicalised language.
Normalisation Trust and Comfort Reducing self-stigma – Empowering Hope	"meeting a recovered person with a mental illness made me feel normal and not different"  I could talk about things I didn't feel comfortable talking about with a health professional. The peer worker helped me to like myself better and understand myself more, to believe in my own potential and to achieve my goals".  Identifies that these aspects can extend to carer perspective — "meeting a young person similar in age to our son with the same illness has given us hope for our son"
Plugging the gaps – supporting role of Peers for	Strong theme of plugging the gaps by MHS - PSW's responding more promptly to support consumers where mhs not able to do so. Bridging relationship between SU's and MHS – both instrumental and relationship factors:
TO A SECTION OF THE PERSON OF	Credibility through lived experience identified as a way to establish rapport ("it eases the patient's anxiety at discharge which is demonstrated by the trusting atmospherebetween patient and peer"; and build bridges that some professionals struggle with—both in terms of the relationship and processes—"help the flow of information and consumer care between us and the inpatient ward". [non-SU quotes]
	This paper's findings would have been improved by focusing on fewer perspectives so that the depth of analysis could have been deeper and supported by more quotes – would have increased plausibility.
	SU perspective is provided by SU's but also by "referrers" and "GPs" - would have been helpful to see SU quotes to back up these impressions.
"Underlined" - Service User quotes;	"Underlined" - Service User quotes; normal text - study Author's interpretations; / takes - Reviewer's paraphrase of study Author's interpretations. Badd Raks are initial emerging synthesising themes.

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article. Henderson et al., (2013). (6/8)

kesearch characteristics characteristics Peer Chara											,, 0,	,,								٠,٠	,,,,,	, (4	ш.,		J11	
characteristics Peer Support  Service users - Individual. N = 9. Focused on perceptions of peer "healthy lifestyle Australian Caucasian.  Seven Caucasian.  Caucasian.  Characteristics Peer Aims  Support To identify Focus group: Nominal consumer technique the influence al., 1975) the miduence al., 1975) actificated by lives.  Facilitated by Caucasian.  Ranked. Service user quotes.  Service users - Individual. To identify Focus group: Motivation (15 votes) "Small sample Social interaction size".  Social interaction (15 votes) "Small sample Healthy lifestyle (9) "Cender bias."  Facilitated by (8). Building confidence the authors.  Service user quotes. Service user quotes. Challenges."  Service user quotes. Challenges."  Explanatory model - "Cycle of Support"." "ach components to make lifestyle than of received as a slight, but emaintain positive changes."	Context	Australia.		Statutory	mental hearn	agencies																				
cetristics Peer Aims  Support  E users - Individual. To identify Focus group male. encouraging of peer "healthy digenous lifestyle lian behaviours" peer support head on their the authors.  sian. Support and support and on their the authors.  Service user quotes of support" - "cach excluding the maintain positive behaviour facilitate and maintain positive behaviour slight, but components to facilitate and maintain positive behaviour changes."  Limitations  Limitations  Limitations  Limitations  Limitations  Limitations  Limitations  Limitations  Scal interaction size".  Gender bias."  Gender bias."  Gender bias."  Focus group Healthy lifestyle (9) Gender bias."  Gender bias."  Focus on Building confidence excluding the excluding the excluding the excluding the maintain positive behaviour change."  Explanatory model - "Cycle of Suppon"."	Researcher characteristics	University	researcher with	peer-research	background	(AH) and	second author,	(VK),	qualitative	nursing	researcher, no	peer research	background.		AH declares	"possible vested	interest in	positive	outcome, First	author "offset	this potential	bias" - no	previous	research interest	in peer support.	
Aims    Construction   Findings   Aims	Participant characteristics	Service users -	N=9.	1000/	100% mate.	One indigenous	Australian	The state of the s	One	Micronesian	2	Seven	Caucasian.													
Focus group: Motivation (15 votes) "Small sample Social interaction group (21) Healthy lifestyle (9) (21) Healthy lifestyle (9) (22) "Gender bias." (23) Positive mental attitude (9) Building confidence the authors.  Tape recorded. Service user quotes. Tape recorded. "Cyclic phenomenon of support" – "each of support" – "each of supports to facilitate and maintain positive behaviour change." "Explanatory model – "Cycle of Support". "Explanatory model – "Cycle of Support".	Type of Peer Support	Individual.		rocussed on	encouraging	healthy	litestyle	behaviours																		
J. Motivation (15 votes) "Small sample Social interaction (11) Healthy lifestyle (9) "Gender bias." Positive mental attitude (9) Building confidence (8).  Service user quotes.  "Cyclic phenomenon of support"—"each of the 5 components reinforced the other components to facilitate and maintain positive behaviour change."  "Explanatory model—"Cycle of Support".	Research Aims	To identify	consumer	perceptions	ofpeer	support and	the influence	peer support	had on their	lives.																
festyle (9) "Gender bias." hental ) "Focus on confidence exploration of benefits, while excluding the excluding th	Method	Focus group:	Nominal	group	technique	(Delbecq et	al., 1975)		Facilitated by	the authors.	Tape recorded		Ranked.													
der bias."  der bias."  us on  us on  ration of fits, while ding the enges."  out and  uragement excived as a  t, but ed ppts to lifestyle ges.	Findings	Motivation (15 votes)	Social interaction	(11)	Healthy lifestyle (9)	Positive mental	attitude (9)	Building confidence	(8).		Service user quotes.		"Cyclic phenomenon	of support" - "each	of the 5 components	reinforced the other	components to	facilitate and	maintain positive	behaviour change."		"Explanatory model –	"Cycle of Support".			
ons  Longitudinal studies recommended - "as peer support is ongoing, it is unknown whether gains made will be sustained when the peer relationship ends"  Recommends gender differences research about given and perceived support.  "Gender relevant for clinical practice"	Limitations	"Small sample	size".		"Gender bias."		"Focus on	exploration of	benefits, while	excluding the	challenges."		Support and	encouragement	not received as a	slight, but	enabled ppts to	make lifestyle	changes.							
	Recommendati ons	Longitudinal	studies	recommended -	"as peer support	is ongoing, it is	unknown	whether gains	made will be	sustained when	the peer	relationship	ends"		Recommends	gender	differences	research about	given and	perceived	support.		"Gender	relevant for	clinical	practice"

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Henderson et al., (2013). (6/8)

Ney I licilies
Motivation – linked with healthy life style support Increased Social Interaction Positive mental attitude and increase in confidence – linked with increased sense of autonomy – self-
efficacy.

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article. Davidson et al., (2001) (7/8)

United States.  Community based programme	Context
"Experienced qualitative researchers". University researchers or researcher-clinicians Not reported if any researcher allied with the program under evaluation.	Researcher characteristic s
support arm) (7 – non-peer; 7 stipend only – total N of 21) Living in the community In receipt of out-patient psychiatric treatment, DSM-IIIR diagnosis (psychotic/ major affective /personality disorder, Moderate to severe impairment in social/occ functioning as rated by clinician.	Participant characteristics
Voluntary (expenses covered only) Individual.	Type of Peer Support
Qualitative aspects formed part of a separately reported quantitative report on RCT: "Investigating impact of supported friendships on social functioning wellbeing, QoL, self-esteem, service use and satisfaction of socially isolated individuals living in the community"  To evaluate the "Partnership Project" – supported socialisation approach – 9 month period - \$28 stipend/month to access social and recreational activities together.	Research Aims
Phenomenological (Davidson, 1994, Davidson et al., 1995, Giorgi, 1970, Wertz, 1983).  Randomised control trial – Peer arm, Non- Peer arm, and stipend-only arm.  Qualitative aspects reported only in this article.  Semi-structured interviews & focus groups – ppts "encouraged to provide narrative responses to open- ended [questions]".  45-90 mins, taped.  Themes were shared with subset of ppts for feedback/input.	Method
Themes – "life before the program (Loneliness, and isolation; demoralisation and estrangement)  Crowing a friendship, the more you get out, the better you get out, the better you feel, I wasn't by myself, we were just at the same level, expanding networks, finding networks, finding a place in the world,  Service user quotes.	Findings
5 ppts declined to be interviewed – so may be positively skewed.	Limitations
Recommends "mediated structures" argues for mental health rehab to be seen as something that should happen within a "supported community life" – where adjustments are made to minimise effects of mental illness throughout the physical and social environment. Emphasis on wider social policy/Prejudi ce/Disability.	Recommenda tions

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Davidson et al., 2001. (7/8)

Key Themes	Illustrative Quotes to Support Themes
Before the programme: Loneliness, emptiness, and isolation; demoralisation and estrangement	Social isolation of individuals linked to the nature of the disability itself - negative picture of "expert" literature. First person account very different – enduring but unfulfilled desire for love, warmth and friendship -social stigma – leading to internalised stigma – lack of opportunity for establishing meaningful, reciprocal relationships with peers outside of the formal mental health system.  many lonely days just waitingfor someone to call me upit was no fun. I found it a very lonely and isolated feeling"
	Passivity, lack of self-esteem, self-confidence — "locked inside the miserylike being sickbeing nauscated or having a bad headacheit's a distraction" - need for a softer transition via supported socialisation into social contact/friendships. "It's like youcan't get involved because you're not sort of all there".  (someone who understands my mental illness — not having to explain that?) — transition role of PSW?
During the programme:  Show me  Growing a friendship, the	Professionals (MHW's, psychiatrists, nurses – often only non-family contact) – "I did have friends, the mental health organisation that I'm working with, they were like my friends, althoughit's basically a professional type of relationship, so it's not real, you like confiding. I mean you could confide in them but it's not the same as having a close friend" Something here about "real" friendship – being able to confide – hints at PSW role as a half-way-house between prof and real friendships?? Confiding (via LE?) – hints at TR.
you feel, I wasn't by myself, we were just at the same level, expanding networks, finding a place in the world,	Acceptance – through the "peer" element – "palpable "welcome" from the very first meeting" – Service users commented that seeing that their partner (here peer or non-peer) came back time after time and even after times when they were having a bad day, to be very important – again concrete demonstration. "she never let me go when I couldn't see her, she came to me. She never let me go." Clinical implications here around the importance of demonstratively secure therapeutic relationships?
Easing the pressure	For some doing "normal things with normal people" really helped.
Transitional role	"But he understands mental illness a little, so he's not really stigmatizing me for mental illness because he has ithe didn't stigmatize mebecause he is mentally ill."
Establishing common ground Inspiration – Role modelling – imagined	"Male bonding"we're both on medication. We've both been in hospitals. So there was that kind of bonding too".  Ppts made comparisons with their peer partners that went both ways — "my partner teaches me how to sail and I teach him how to fish".  Only difference for one was driving: "that he drives and I don't, and that he does certain things that I don't, but I do certain things that he does n't"
nume	Imspiration: "my partner is mentally ill but to an extent he's fairly, you know, with it". Enabled them to imagine (sense of ppts inner world here) – a positive future – aspiring to alternative visions of the future.

"Underlined" - Service User quotes; normal text. - study Author's interpretations; Italics - Reviewer's paraphrase of study Author's interpretations. Bold Italics are initial emerging synthesising themes.

**Appendix B:** Data extraction Form I: Summary Characteristics of Selected Article Salyers et al., (2009) (8/8)

,		,						
	Context	Researcher characteristic	Participant characteristics	Type of Peer Support	Research Aims	Method	Findings	
		Se.						
	United	One	Service users	1 paid PSW	To explore	"Open-ended	Being able to	
	States	interviewer/res	N= 14 - those	employed	experiences of	interviews"	relate due to	structured
		earcher - "a	ppts who	through funding	staff and	(semi-	lived	
	Statutory -	manager at the	completed the	for this pilot.	consumers	structured).	experience	
	community	agency, and	9-month follow-		regarding the			
	mental	was well-	up and whom	Formalised,	program - part	"What has been	Optimism and	
	health team	known to staff	the qualitative	trained.	of a larger	biggest change	positive	PSW
	(ACI)	and possibly	data is based.	Peer-provided	mixed-methods	since	attitude	
		to some	fourt of a total N	"Illness	study to	implementing	Encouragemen	
		consumers".	(out of a total iv	Management	evaluate impact	TMIK! What	-	
		Other authors	01.17)	and Recovery	of integrating	think		
		University	Characteristics 2 1	(IMR)" -	assertive	contributed to	Motivation	Ior PSW
		band	reported for 11	manualised	community	that abanca?	and Hope -	
		based	of the 14 ppts -	carried out in	treatment with	that change/	role	Unable to
		researchers.	just under half	the service-	peer-led IMR	what was	modelling,	attribute success
			female, mostly	user's home.		holostreas	better self-	to "Peer" aspect
			schizo-			neibini about	management	or if due to
			affective/schizo			the program?	of illness,	personality,
			phrenia			what is it like	improved	skills, or the
			diagnoses.			consumer-	relationships.	IMR materials
						provider?	Some	
							reporting of	study - only a
							themes with	
							quotes, some	
							secondary	
							level	
							interpretation.	

**Appendix B:** Data extraction Form II: Table of Key Findings and Supporting Data extracts. Salyers et al., 2009. (8/8)

Key Themes	Illustrative Quotes to Support Themes
Being able to relate due to lived experience	"She's gone through [the] same thing. I can relate to her better. If she can do it, why can't I do it?" "She can relate because she has been through it".
Optimism and positive attitude Encouragement	"She told me that I have potential. It's encouraging." (But what was this like to hear this, and what enabled this conversation – for it to be credible?) (10 ppts, 71% agreed with this – would have bene good to see more comments)  Hope and Motivation as biggest change.
Motivation and Hope – role modelling, better self-management of illness, improved relationships	"Being able to know somebody has a mental illness and can get a job. I feel like I can get a job maybe not right away, but down the road". Sense of internal processes here of imagining what they might need to change before they're ready, but also that it might be possible- imagining brighter future – through role modelling.
-	Staff commented that this hope is contagious – "it gives us hope too" Involvement in meaningful activities – 5 ppts – volunteering, church involvement, pursuing hobbies, education. Self-management (4 ppts) and improve relationships (3) – lack of consumer perspective data in paper.
	Only with 1 PSW – limited as a pilot – was it her skill or was it her "peer" role?
	Author explanation – reports consumers demonstrating increase in "perceived recovery" and a trend towards increased knowledge about mental illness – self-efficacy?
	Greater confidence to try new things – better illness management – improved sense of hope.  Consistent with definitions of recovery in literature - Hope seen as single biggest factor from employing the peer specialist.  Delivery of a manualised programme aimed to overcome role ambiguity/tokenism.  Strong inter-personal skills of the peer cited as important – positive attitude, caring nature, assertiveness, and communication skills.  Importance of on-going supervision highlighted – their peer lacked this.  Pilot nature of study and 1 peer precludes firm conclusions.

"Underlined" - Service User quotes; normal text - study Author's interpretations; I talks - Reviewer's paraphrase of study Author's interpretations. Bidd Italks are initial emerging synthesising themes

### **Appendix C:** Semi-Structured Interview Schedule

#### **Introductions**

• Please could you tell me a bit about yourself? How would you describe yourself?

## How they came to work with a PSW

- Could you tell me about how you came to first work with a PSW?
- How did it happen/come about for you?
- Can you tell me about your first impressions?
- What do you remember about your early thoughts/impressions about working with them?
- Has this changed? Why/How?
- How/Was the PSW role explained to you?
- Can you tell me about what you thought about getting a PSW to begin with? Did this change? How/why?

## How it is now with their PSW

• Looking back, what do you make of working with a PSW? How has your impression changed over time? Why do you think that is?

## Comparing PSW support with more traditional support/interventions

- What can you tell me about the support from the PSW and other types of support you've had?
- How has working with a PSW different/same? What do you make of these differences/similarities?
- What about the type of support you've had for your mental health before you began working with the PSW?
- Did you/why did you think having a PSW would be different/same to other types of support you'd had?
- Were your first impressions accurate do you think?

## The relationship

- How would you describe the relationship between you and your PSW? Did it turn out how you thought? Has it changed with time? What things changed it? How was it same/different to other types of relationships you've had?
- What sort of things did you talk about together? What did you do together? What was it like?
- Did you ever discuss mental health? Did you talk about their own experiences of being a service-user and having mental health difficulties?
  - How did you find this? What was it like to talk about these things with the PSW? What do you think about sharing experiences? What effect did/does this have on your relationship with the PSW? What

- effect does this have on how you view them? How do you think the PSW sees you?
- Have you ever had any thoughts about what it is like for them to be a PSW?

## **Impact**

- The way you described yourself at the start of the interview is that the same as you would have described yourself before you worked with your PSW?
- If it's changed, what do you put that down to?/make sense of that/explain that? What impact do you think it's had on you overall?
- How would other people describe you now? (if sense of change)

#### **Future**

- Would you ever consider becoming a PSW in the future? If you've discussed working with a PSW with others, can you tell me about what you've said?
- What advice would you give to PSWs? What would you say to PSWs?
- What advice would you give to other people thinking about working with a PSW?

## **Endings**

• Is there anything else you'd like to add? Is there anything else you'd like to ask me?

Thank you so much for agreeing to be interviewed today.

## Prompts to include, whenever appropriate, to elicit more detail:

How?

Why?

Can you tell me what you remember most about that?

Tell me what you were thinking when that happened?

How did you feel? Can you tell me what this was like for you?

Are you ok to tell me more about that?

If not, why not, if yes, why?/How? [If the same/different], how and why?

I'm really interested in the bit when you said...can you tell me more about that please, if you're ok to?

What do you mean by [...]?

## **Appendix D:** Letter of Introduction







Louise Mullineaux Trainee Clinical Psychologist University of East Anglia Norwich Research Park Norwich Norfolk NR4 7TJ

[Date]

Dear [Name]

I am a Trainee Clinical Psychologist currently working in Norfolk and Suffolk NHS Foundation Trust (NSFT), and as part of my doctoral training, I will be carrying out a research project into service-user experiences of working with a Peer Support Worker.

I am looking to recruit 6-8 service-user participants across Norfolk and Suffolk, who would be willing to be interviewed for up to 90 minutes on their personal experiences of working with a PSW. Participants will be compensated for their time with a £10 shopping voucher, and they would have the opportunity to contribute to a new area of research. The study is non-evaluative in relation to PSWs, and instead will focus on personal, subjective experience.

The study has received full NHS ethical approval and is supported by the University of East Anglia Clinical Psychology program, with supervision provided by Dr. Deirdre Williams (Clinical Lecturer, UEA and Clinical Psychologist, NSFT).

I would greatly appreciate your support in allowing me to come and talk to your team to explain the study in more detail. Advertising material and a copy of the participant information sheet is enclosed. Thank you for your time.

Sincerely,

Louise Mullineaux, Trainee Clinical Psychologist.

## **Appendix E:** Participant Information Sheet







## Participant Information Sheet

# "Service-user experiences of Peer Support Workers in Secondary Adult Mental Health: A Qualitative Research Study."

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done, and what it would involve for you.

Please ask if there is anything that you don't understand or if you have any questions. You can contact us by email, or write to us using the contact details below.

#### Who are the Researchers?

If you would like to discuss anyth	ning in this information sheet,	or wish to
discuss taking part in the research, plea	se contact <b>Louise Mullineaux</b>	(Principal
Investigator) at	; or telephone:	; or the
Project Supervisor,		

## What's involved?

The aim of this study will be to explore, through interviews, the experiences of people who have received support from a Peer Support Worker (PSW) as part of their care from an Adult Community Mental Health Team.

We are interesting in talking to you to find out what it was like for you to work with a PSW, and how you found the experience, personally as someone who has had or has a mental health condition.

You need to have had at least about 6 hours of individual contact, so that you have enough to say about the experience because the interview will be quite detailed. Participants will be interviewed individually. The interview will be tape recorded and a word-for-word transcript of what was said in the interview prepared. The total time for the interview will be no longer than about 90 minutes, and it could be shorter.

Researching the personal experience of service users in this context has not, to our knowledge, been done before, and we feel that this is an important gap in the research.

## Do I have to take part?

No, it is up to you to decide if you want to join the study or not. If you do agree to take part, we will ask you to sign the consent form which is attached to this information sheet.

## Will my taking part in the study be kept confidential?

We take your confidentiality very seriously. However, it is important that you understand that in this type of research it is not possible to promise complete anonymity. This means that there is a small chance that you may be identifiable from the information you provide – although we will take a lot of care to not include information that could identify you, we cannot guarantee 100% that others may not guess, especially if they know you are participating in the study. This is because sometimes quotes from your interviews are used to support arguments being made by the researcher in the Analysis section of the final report.

The outcomes of the study may be published in an academic journal so that what is learned in this research can be shared to help others. However, at the start of the interview, you will be offered the chance to choose a different name for the study to protect your real identity.

You will be asked to complete a short demographic questionnaire, which will help us to describe our overall sample in terms of such things as age, ethnicity and experiences of mental health care. This is important in this type of research because some of these differences may be relevant to your experience of working with a Peer Support Worker. We may need to check the demographic information you provide to us by checking it is the same as the information that your mental health team have about you. This is to ensure that we have your correct address if you choose to do the interview at home, and that there are no reasons why participation in the study would be inappropriate for you at this time.

If during the interview you tell the researcher things about another person which could mean that people reading the transcript could guess who you were talking about, we will not use these, or change the identifying parts, in the written report.

The person who normally manages your care will know that you have been asked to take part, and if you choose to participate, a copy of your consent form will be put on your medical file. You can speak to other people about the study if you wish.

If, during the research interview, you tell the researcher something which makes them concerned that you or someone else may be at risk of harm, it is

possible that this information may have to be shared with manager responsible for your care, or with your GP. You would be told before this happened and whenever possible the situation would be discussed openly with you so that you understand why it was necessary to break confidentiality.

On rare occasions it is necessary to break confidentiality without letting a participant know, but this is only done if telling you first would jeopardise your safety or the safety of someone else.

# What will you do with the information from my interview?

After all participants have been interviewed, the transcripts will be carefully analysed and checked for accuracy. However, this will not be done for **21 days after the interview** to give you time to change your mind and withdraw from the study. If you choose to do this, your data will not be used and will be destroyed.

The tape recording will be immediately transferred from the recording device to a secure, encrypted laptop or desktop computer, and the original recording deleted. If this cannot be done immediately it will be transferred onto a secure, encrypted memory stick and then transferred as soon as possible to the encrypted computer hard-drive.

A hard copy of the interview transcript will be stored in a locked filing cabinet at a secure location. All data will be stored according to current data protection legislation and will be destroyed after 10 years.

# Are there any possible disadvantages of taking part?

It can be tiring talking to someone new, and it is possible that talking may bring up feelings – some good or some bad, although care will be taken and your privacy will be respected. If you do feel upset or just need a break, please tell the researcher who will be able to provide reassurance and offer a break. The interview can even be stopped for the day and another time re-arranged to complete it. If you want more support, I will put you in touch with the mental health team normally responsible for your care.

The interviews will take up to 90 minutes and you will <u>not</u> be paid for your time, although there is a small incentive of a £10 shopping voucher as a thank you for taking part. You can do the interview at your home, but if you choose to do the interview on NHS premises or at the UEA, unfortunately you will need to pay for your own transport and parking costs.

# Are there any possible benefits of taking part?

There are no expected direct benefits for participants. However, some people find that having the chance to talk to someone in detail about an experience very helpful, and it can feel good to put into words something which you may not have spoken about before.

You will also be taking part in research that is asking a question that nobody has asked before. You will be contributing to improving our general understanding of what it is like for people in similar contexts to you to work with a Peer Support Worker. This new information may be helpful in training and supporting Peer Support Workers which could benefit future service-users.

# What happens if I start the study and then decide I don't want to carry on?

You can change your mind and you do not have to explain v	vhy. You have	
the right to withdraw your participation at any time, up to and incl	uding the end of	
the <b>21st day</b> after your interview. There is a time limit on this beca	use it is very	
difficult to take out data from this type of analysis. You will need to let Louise or		
Deirdre (the researchers) know that you have changed your mind.	Louise (Principal	
Investigator) can be contacted by email at	, or telephone:	
, or you can contact the Project Supervisor	via	

# What if there is a problem?

If you have any concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

Alternatively, you can also contact	_	(Director of	the UEA
Clinical Psychology Course:	).		

# Who has reviewed the study and how is it funded?

The study has been checked at several stages during planning by service user research-panels, UEA internal review panels, and has received full NHS ethical approval from the Leicester Central Research Ethics Committee.

This research study is being carried out as part of a training course that the researcher is doing. There is no research grant or funding associated with this study, apart from a small budget to cover costs such as photocopying and postage stamps.

# What will you do with the research findings?

The findings of the research will be shared with the participants there will be dedicated time for you to discuss the findings and to reflect on what it was like for you to be involved (this is usually called the "debrief").

It is important to share the results of research so that other people who are interested in this area can learn about what this research found. This could be verbally or in writing, and could be within this NHS Trust or it could also be to external organisations with an interest in Peer Support.

The findings will also be written up and it is possible that the write-up could be published in an academic journal. It is also likely that a summary of the research

will be put into a special type of poster for display at a research conference, where lots of different research projects will be discussed, or that the researcher will present a summary of the main findings by doing a presentation.

If you think you would be interested in taking part, please let Louise or know and we will be happy to discuss this with you.

Thank you for reading!

# **Appendix F:** Consent form







Participant ID: CONSENT FORM

Participant ID:	CONSENT FORM		
Title of Project: Service-user E	experiences of Peer Support Worker	rs in Secondary Adult Mental Health	
Name of Researcher: Louise Number here].	Aullineaux. [email:	; Tel: insert study mobile	
		Pleas	e initial bo
(Version 3.1 08/03/20	read and understood the Participant 016) and I have had the opportunity to vered to my satisfaction.		
I confirm that I am sig had the study explain	ning this consent form at least 48 ho ed to me.	ours after having first	
3.I understand that releva	ant sections of my medical notes and	data collected during	
the study, may be loo	ked at by individuals from the Unive	rsity of East Anglia, regulatory	
authorities or from th	e NHS Trust, where it is relevant to r	my taking part in this research. I give	
permission for these i	individuals to have access to my reco	ords.	
	participation is completely voluntary ason, without my medical or legal rig		
5. I understand that the	interview will be tape-recorded and	the file securely stored.	
	olute anonymity cannot be guarante are will be taken to remove identifyi		
	and withdraw my interview data from a second and a second with the research and the research and the research are second as the research and the second are second as the s	om the study up to 21 days after the rcher to let her know.	
8. I agree to take part in	the above study.		
Name of Participant	Signature	Date	
Name of Researcher	Signature	Date	

Please complete the following information sheet in as much detail as you are willing to. We are collecting this information because it is helpful to understand how similar or different participants are to one another. This helps us to understand if different experiences could be partly to do with background factors like where you live, or your age.

# **A:** For long have you worked with a Peer Support Worker (approximately)?

# **B:** Information about you:

- 1. What is your gender? (Please circle an option).
  - a. Male
  - b. Female
  - c. Other
- 2. How old are you? (Please circle an option).
  - a) 18-34
  - b) 35-50
  - c) 51-65
  - d) 65+
- 3. Do you live in a town/city, or in the countryside?
- 4. What is your ethnic group? Circle or tick **one option** that best describes your ethnic group or background:

White

Mixed/Multiple ethnic groups

Asian/Asian British

Please turn over.

# Black/ African/Caribbean/Black British

Other ethnic group

# **B:** Information about your mental health condition:

- 1. How long have you been a user of secondary adult mental health services?
  - a. Less than 1 year
  - b. 1 -2 years
  - c. 3-5 years
  - d. 6 years or more.
- 2. What sort of other help have you had for your mental health condition from the mental health team (or elsewhere). This should be different to your work with the Peer Support Worker (like nursing care or talking to a psychiatrist).

Thank you for completing this form.







# Volunteers needed for a research study exploring service-user experiences of working with a Peer Support Worker.

We would like to find out what it's been like for you, and are interested to hear your thoughts and feelings about your experience. We are carrying out research exploring personal experiences of working with a Peer Support Worker.

For more information, or if you are interested in taking part, please contact:

Louise Mullineaux (Trainee Clinical Psychologist)

or

(insert study mobile number here)



## East Midlands - Leicester Central Research Ethics Committ

The Old Cha Royal Standard Pl Nottingh NG1 (

Telephone: 0207 104 8

15 March 2016

Ms Louise M Mullineaux Trainee Clinical Psychologist Cambridge and Peterborough NHS Foundation Trust Elizabeth House Fulbourn Hospital Fulbourn Cambridge CB21 5EF

#### Dear Ms Mullineaux

Study title:	Service User Experiences of Peer Support Workers in an Adult
	Community Mental Health Service: An Interpretative
	Phenomenological Analysis.
REC reference:	16/EM/0109
Protocol number:	N/A
IRAS project ID:	183257

Thank you for your letter of 11 March 2016, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Ms Helen Poole, nrescommittee.eastmidlands-leicester@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### Confirmation of ethical opinion

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

# Conditions of the favourable opinion

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

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

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

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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

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

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact <a href="https://example.com/hra.studyregistration@nhs.net">https://example.com/hra.studyregistration@nhs.net</a>. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

# Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	2.0	13 December 2015
Covering letter on headed paper	1.0	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance and indemnity letter]	1	08 February 2016
Interview schedules or topic guides for participants [Semi-structured interview guide.]	2.0	13 December 2015
Letter from sponsor [Confirmation of UEA sponsorship]	1.0	05 February 2016
Non-validated questionnaire		
Other [HCPC 2015 CV Imogen Hobbis]	1.0	09 February 2016
Other [Letter of Introduction to Gatekeepers.]	1.1	10 March 2016
Other [Participant Demographic Questionnaire]	3.0	10 March 2016
Participant consent form [Consent form]	4.1	11 March 2016
Participant information sheet (PIS) [Participant Information Sheet]	3.1	08 March 2016
REC Application Form [REC_Form_25022016]		25 February 2016
Referee's report or other scientific critique report [Review from Norfolk and Suffolk NHS Foundation Trust's Research Panel]	1	08 February 2016
Referee's report or other scientific critique report [Louise Mullineaux Thesis Proposal Feedback]	1.0	18 August 2015
Referee's report or other scientific critique report [INSPIRE feedback for thesis proposal Louise Mullineaux]	1.0	26 June 2015
Research protocol or project proposal [Proposal protocol]	3.0	05 January 2016
Summary CV for Chief Investigator (CI) [Louise Mullineaux CV]	1.0	08 February 2016
Summary CV for student	1.0	08 February 2016
Summary CV for supervisor (student research) [CV Deirdre Williams]		08 February 2016

# Statement of compliance

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

# After ethical review

# Reporting requirements

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

Notifying substantial amendments

- · Adding new sites and investigators
- · Notification of serious breaches of the protocol
- Progress and safety reports
- · Notifying the end of the study

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

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <a href="http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance">http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance</a>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

#### 16/EM/0109

Please quote this number on all correspondence

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

Yours sincerely

Klode 💂

Mr John Baker Vice Chair

Email: nrescommittee.eastmidlands-leicester@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mrs Sue Steel

Dr Bonnie Teague, NHS

# Norfolk and Suffolk MIS

NHS Foundation Trust

Research and Development
The Knowledge Centre
Hellesdon Hospital
Drayton High Road
Norwich

Telephone 01603 421255 E mail: RDofficemailbox@nsft.nhs.uk

Ms Louise M Mullineaux
Trainee Clinical Psychologist
Cambridge and Peterborough NHS Foundation Trust
Elizabeth House
Fulbourn Hospital
Fulbourn Cambridge
CB21 5EF

27th May 2016

Dear Ms Mullineuax,

Re: RD #16 183257 Service User Experiences of Peer Support Workers in an Adult Community Mental Health Service: An Interpretative Phenomenological Analysis

Thank you for submitting the above project for local research governance approval. I am pleased to inform you that your project has been given full approval and you may begin your research at the following site:

Norfolk & Suffolk NHS Foundation\_Trust

I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign both copies returning one copy to the Research and Development office, at the above address, and keeping the other in your study file. Failure to return the standard terms and conditions may affect the conditions of approval. Under the agreed Standard Terms and Conditions of Approval you must inform the R&D department of any proposed changes to this study and submit annual progress reports to the R&D department.

Any researcher(s) whose substantive employer is not the Norfolk & Suffolk NHS Foundation Trust must have a Letter of Access or Honorary Research contract and evidence of Good Clinical Practice (GCP) training before coming on site to conduct their research in this project. Please note that you cannot take part in this study until you have this documentation. If a Letter of Access / Honorary Research Contract has not been issued – please contact us immediately.

If you have any queries regarding this or any other project, please contact, Tom Rhodes, Senior Research Facilitator, at the above address.

The reference number for this study is: RD #16 183257, and this should be quoted on all correspondence.

Yours sincerely,

Bonnie Teague Care Research Manager

MINDFUL EMPLOYER Chair: Gary Page
Chief Executive: Michael Scott
Trust Headquarters: Hellesdon Hospital,
Drayton High Road, Norwich, NR6 5BE
Tel: 01603 421421 Fax: 01603 421440 www.nsft.nhs.uk





# **Appendix K:** Author Guidelines: *Qualitative Health Research* (QHR)

#### 4. Preparing your manuscript

#### 4.1 Article Format (see previously published articles in QHR for style):

- Title page: Title should be succinct; list all authors and their affiliation; keywords.
   Please upload the title page separately from the main document.
- Blinding: Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- Length: QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

#### Additional Editor's Preferences:

- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

# 4.2 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

## 4.3 Artwork, figures and other graphics

- Figures: Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.
- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e., INSERT TABLE 1 HERE).
- Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.
  - TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
  - Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
  - Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

#### 4.4 Supplementary material

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- 2. Theoretical orientation and evaluation: Is it theoretically clear and coherent? Is there logical progression throughout?
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- 6. Data analysis and findings: Does the analysis of data reflect depth and coherence? In-depth descriptive and interpretive dimensions? Creative and insightful analysis? Linked with theory?

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# 5. Submitting your manuscript

# 5.1 How to submit your manuscript

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