# Experience, Recovery and Positive Changes in Psychosis

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**THESIS PORTFOLIO: CANDIDATE DECLARATION**

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| **Declaration and signature of candidate** |
| I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.  I confirm that the decision to submit this thesis is my own.  I confirm that except where explicitly stated, the work has not been submitted for another academic award.  I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.  Signed Date: 29/06/2023 |

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Table of Contents

[Experience, Recovery and Positive Changes in Psychosis 1](#_Toc144071542)

[Thesis Abstract 7](#_Toc144071543)

[Paper 1: Literature Review 8](#_Toc144071544)

[Peer support work within Early Intervention services for Psychosis: A review of the literature 8](#_Toc144071545)

[Abstract 9](#_Toc144071546)

[Introduction 10](#_Toc144071547)

[Aims and Objectives 12](#_Toc144071548)

[Method 12](#_Toc144071549)

[Electronic databases 12](#_Toc144071550)

[Inclusion and Exclusion criteria 13](#_Toc144071551)

[Data collection 13](#_Toc144071552)

[Critical appraisal and bias analysis 13](#_Toc144071553)

[Data analysis and synthesis 14](#_Toc144071554)

[Results 16](#_Toc144071555)

[Study selection 16](#_Toc144071556)

[Study Characteristics 16](#_Toc144071557)

[Qualitative – Randomised Control Trials 17](#_Toc144071558)

[Mixed Methods 19](#_Toc144071559)

[Qualitative 21](#_Toc144071560)

[Discussion 24](#_Toc144071561)

[Limitations 30](#_Toc144071562)

[Clinical Implications 31](#_Toc144071563)

[Future research directions 31](#_Toc144071564)

[Conclusion 32](#_Toc144071565)

[References 33](#_Toc144071566)

[Table 1. Data Extraction form 41](#_Toc144071567)

[Paper 2: Empirical Paper 46](#_Toc144071568)

[Positive Changes Following an Experience of Psychosis: A Grounded Theory Exploration 46](#_Toc144071569)

[Abstract 47](#_Toc144071570)

[Introduction 49](#_Toc144071571)

[What Is Psychosis? 49](#_Toc144071572)

[The Experience of Psychosis 50](#_Toc144071573)

[Positive Changes Following Psychosis 50](#_Toc144071574)

[Aims and Research Question 51](#_Toc144071575)

[Methodology 52](#_Toc144071576)

[Epistemological Position 52](#_Toc144071577)

[Grounded Theory 52](#_Toc144071578)

[Ethics 53](#_Toc144071579)

[Participants and Recruitment 54](#_Toc144071580)

[Data Collection and Analysis 55](#_Toc144071581)

[Reflexivity and Retroductive Reasoning 56](#_Toc144071582)

[Results 57](#_Toc144071583)

[Psychosis Experience 57](#_Toc144071584)

[Initial Perceptions of Psychosis Experience 59](#_Toc144071585)

[Positive Changes 61](#_Toc144071586)

[Internal/ External Catalyst for Change 64](#_Toc144071587)

[Maintenance of Positive Changes 67](#_Toc144071588)

[Emergent Theory Diagram 68](#_Toc144071589)

[Discussion 69](#_Toc144071590)

[Emergent Theory and Links to Current Literature 69](#_Toc144071591)

[Clinical Implications and Recommendations 73](#_Toc144071592)

[Limitations 74](#_Toc144071593)

[Future Research 75](#_Toc144071594)

[Conclusion 75](#_Toc144071595)

[References 76](#_Toc144071596)

[Appendix 83](#_Toc144071597)

[Appendix 1 – Formatting Guidance and Template for Authors 83](#_Toc144071598)

[Appendix 2 – Recruitment Poster 86](#_Toc144071599)

[Appendix 3 – Information Sheet 87](#_Toc144071600)

[Appendix 4 – Consent Form 93](#_Toc144071601)

[Appendix 5 – Debrief Form 95](#_Toc144071602)

[Appendix 6 – Example Questions 99](#_Toc144071603)

[Appendix 7.1 – Example Transcript (Miranda) Open Coding 100](#_Toc144071604)

[Appendix 7.2 – Example Transcript (Miranda) Selective & Theoretical Coding 101](#_Toc144071605)

[Appendix 8 – Example Memo from Participant 6 102](#_Toc144071606)

[Appendix 9 – Extract from Reflective Log 103](#_Toc144071607)

[Paper 3: Executive Summary 104](#_Toc144071608)

[Positive Changes Following an Experience of Psychosis: A Grounded Theory Exploration 104](#_Toc144071609)

[What is an executive summary and who is it for? 105](#_Toc144071610)

[Project Summary 105](#_Toc144071611)

[Background Information 106](#_Toc144071612)

[Study Information 106](#_Toc144071613)

[Steps in data collection 106](#_Toc144071614)

[The Theory 108](#_Toc144071615)

[Explanation of the Theory 109](#_Toc144071616)

[How it all fits together 112](#_Toc144071617)

[Discussion 113](#_Toc144071618)

[Limitations and Future Research 113](#_Toc144071619)

[Recommendations and Clinical Implications 114](#_Toc144071620)

[Conclusion 114](#_Toc144071621)

[Messages from the Participants 115](#_Toc144071622)

# Thesis Abstract

The purpose of this thesis is to explore the experience of psychosis, specifically positive changes and recovery following this experience, aiming to provide a novel insight into the phenomena. This was achieved through collating and analysing current research, and through the development of a theory exploring the experience of positive changes following psychosis.

A literature review was completed that sought to synthesise current literature on the use and efficacy of Peer Support (PS) within the context of Early Intervention (EI) Services. Nine papers were identified that explored and evaluated the use and experience of PS. The review identified several reported benefits both for those directly experiencing psychosis, their friends and family members and Health Care Professionals. The key benefits of engaging in PS were the reduction of stigma, shame and social isolation as well as improving recovery and encouraging healthier relationships. However, the studies also noted staff attitudes and experience as potential barriers to implementing PS programmes. Finally, there is a lack of research into PS specifically in the context of EI and further research could explore its use and effectiveness.

An empirical paper presents an original piece of research exploring positive changes following an experience of psychosis. The study recruited eight participants, using social media, who identified as having experienced psychosis. These participants took part in interviews which were then analysed by utilising grounded theory methodologies to help in developing a theory. Key categories were identified, ‘Psychosis Experience’, ‘Initial Perceptions of Psychosis Experience’, ‘Internal and External Catalyst for Change’ ‘Positive Changes’ and ‘Maintenance of Positive Changes’ and the theory generated helps to explain how these interact. The results are compared to current research and limitations, clinical recommendations and directions for future research are discussed.

An executive summary, summarising the empirical study in accessible language was also completed.

# Paper 1: Literature Review

## Peer support work within Early Intervention services for Psychosis: A review of the literature

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## Abstract

**Introduction:** Peer Support work (PS) is a recommended part of Early Intervention (EI) Services for First Episode Psychosis (FEP). This review aims to explore the current research and understanding on the use and function of PS in EI services.

**Method:** The review was conducted through a search of the literature using SCOPUS, PubMed, Science Direct, Web of Science, and Cochrane Library with further searches conducted through cross-referencing. The search terms included ‘peer support’, ‘psychosis’ and ‘Early Intervention’.

**Result:**  1107 papers were retrieved which were then reviewed against eligibility criteria including the presence of key words such as Early Intervention, peer support and psychosis being present in the title, abstract or key words. A total of nine papers were reviewed and included in this paper which utilised qualitative, quantitative and mixed methods designs.

**Conclusion:** The review highlighted a number of benefits in the use of PS in EI services both for individuals directly experiencing psychosis, their families and friends and staff members of EI services. The review particularly highlighted the effect that PS can have on reducing stigma and improving recovery and relationships while also demonstrating staff attitudes and experiences as potential barriers to implementing PS in EI services. However, there is a lack of research into PS specifically in the context of EI for psychosis and further research should be conducted to ensure that it is being used correctly.

## Introduction

This review will synthesise the current literature on the use and function of Peer Support Workers (PSW’s) within the context of an Early Intervention (EI) service that specialises in the treatment and support for people currently experiencing a First Episode of Psychosis (FEP). The main reason for exploring the current research into PSW within the context of an EI service in psychosis is that despite being a recommended part of EI work there is relatively little research into this subject. Therefore, a review of the literature would aim to synthesise the current understanding of the implementation of Peer Support (PS) looking to make recommendations for clinical practice. Before beginning the review, it will be prudent to explore some of the definitions and current understanding of psychosis, EI services and the role of PSW.

Psychosis is a common and sometimes debilitating mental health condition that, global prevalence estimates suggest, will affect 1 individual out of every 150 at some point in their lifetime (Moreno-Küstner et al, 2018). The symptoms of psychosis are usually split in to two distinct categories, positive and negative. Positive symptoms make up one such category and encompasses changes in thoughts or feelings that are in a way added to a person’s life, such as delusions, hallucinations and disorganised speech or behaviour (American Psychiatric Association, 2013). Negative symptoms usually reflect a decrease or loss of functioning in the individual, such as a lack of interest in activities or other people, inexpressive facial features and becoming monotonal in their speech, the symptoms of this may not be as evident as those associated with positive symptoms (American Psychiatric Association, 2013). Two negative symptoms that have become of particular interest in the diagnosis of psychosis are a loss of motivation and a reduction in emotional expression (Heckers et al, 2016). FEP can be an extremely disruptive, frightening, and debilitating condition that can, in some instances lead to loss of employment (Rinaldi et al, 2010), increased risk of suicidal ideation, social isolation, feelings of shame and guilt, and in some cases Post-Traumatic Stress Disorder (PTSD) (Mueser et al, 2010). Furthermore, both self-stigma and social stigma is highly present within FEP which can lead to individuals avoiding treatment (Franz et al, 2010) or further isolating from social support (Birchwood et al 2007). It is, therefore, easy to see why there has been a focus on the best way to approach the treatment of FEP.

EI services for psychosis were first introduced in the UK in 1999 with the aim to improve short- and long-term outcomes for clients by reducing the duration of untreated psychosis. Thereby, improving social and familial functioning, quality of life, treatment satisfaction and providing quicker access to medication and psychological support (Neale & Kinnair, 2017). EI services have been shown in numerous studies to have better outcomes when compared to other treatments (Correll et al, 2018; Aceituno et al, 2019). However, that is not to say that EI services are perfect and there are concerns both with long term maintenance of effects (Sherry et al, 2019) and a consistent drop out from treatment, with disengagement rates ranging from 12% to 53% of clients (Mascayano et al, 2021). It has been suggested that reduced effectiveness of EI services could partly be due to this high drop-out rate (Solmi et al 2018). It is, therefore, understandable why there are almost constant changes and improvements being made to guidelines around the development and implementation of an EI service to account for difficulties such as this that are associated with the treatment of FEP.

In line with these improvements NICE guidelines recommend the use of PSW to aid not only in long term recovery but also in aiding with the reduction of stigma (National Institute for Health and Care Excellence [NICE], 2014). Defining PS is difficult as there are multiple types of PS including, spontaneous mutual aid, peer-run self-help, peer-led advocacy, peer-led family support and peer-group interventions (Mahlke et al, 2014). However, despite these differences, the principles of PS share similar characteristics. PS begins with the assumption that there are similarities between individuals’ experiences allowing for a shared understanding to be created that can be used to support one another (Gillard, 2019). This is viewed as being especially true for experiences that cause mental or physical distress (Mead et al, 2001). PS is a system created with the idea that through this shared understanding each person can benefit, with PSWs being considered experts by experience offering insights gained from their own lived experience of distress (Walker & Bryant, 2013). Within the context of this review PSW would be defined as an individual or group with a lived experience of psychosis, either through their own personal experience of FEP or through supporting a family member or close friend.

## Aims and Objectives

This review aims to draw on published literature to help explore the role and effect of PS within the context of EI Services for psychosis. Due to the relative scarcity of literature on this subject the review will encompass all forms of PS, whether this is informal, family, individual, or group. Furthermore, the review will include definitions of PS including, ‘experts by experience’, ‘peer mentor’, ‘peer facilitators’, ‘peer council’, ‘informal peer support’ and any others that occur during the literature searching phase. For the purpose of clarity this paper will use the term PS to describe all forms throughout.

## Method

To aid with this systematic review the structure of the review will follow the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) guidelines (Paige et al, 2021)

### Electronic databases

The following electronic databases were searched in June 2022: SCOPUS, PubMed, Science Direct, Web of Science, and Cochrane Library. The main search terms used were ‘peer support’, ‘psychosis’ and ‘early intervention’. Similar search terms such as ‘peer mentor’ and ‘schizophrenia’ were also included to increase the range of papers that could be included in the results gained from the searches.

A further search was also conducted by cross-referencing cited articles within eligible papers as well as grey literature searches in Google Scholar and Staffordshire University Library using the same search terms.

### Inclusion and Exclusion criteria

Once the search was completed the results from each database was assessed by a single author (CP), to check for eligibility and any duplicates were removed. The title and abstract were searched for the key words ‘early intervention’ and a form of ‘peer support’. Any studies that did not include theses terms were excluded from this review. Due to the relatively low number of papers returned in the results no date limits were set. Furthermore, no age filters for participants were included as EI services include clients from the age of 14 up to 65. Where possible to aid in the exclusion of data the results were filtered by those relating to psychology, psychiatry and clinical psychology. The main reason for this was that the databases being used were providing papers that were not relevant to the topic being searched for. To account for this, a limiter focusing on papers published for psychology and psychiatry journals was included. In the case of any study where eligibility was uncertain the full text was reviewed and assessed against the inclusion and exclusion criteria. Once again due to the lack of research into this topic the review will include studies with qualitative, quantitative, and mixed methods designs.

### Data collection

Data was collected using an extraction form to collate information and results from the papers being reviewed (see Table 1.). This included general information about the studies including, author, year of publication, title, study design, main findings, data collection methods, analysis, demographics, and type of PS intervention.

### Critical appraisal and bias analysis

The studies eligible for this review were also critically appraised using the Critical Appraisal Skills Programme (CASP) checklist, including Randomised Control Trial (RCT) and qualitative CASP checklists (Critical Appraisal Skills Programme UK, 2018). For the Mixed methods study, the Mixed Methods Appraisal Tool (MMAT, 2018) was used. As part of the critical review these tools aided with searching for and recording bias from the studies being reviewed. Bias in the RCT papers will be reviewed using the revised Cochrane risk-of-bias tool for randomised trials (RoB 2; Sterne et al, 2019).

### Data analysis and synthesis

For the purpose of the review and due to the differences in characteristics of the papers including, country, demographics, and the different methods and analysis used in the studies reviewed, qualitative, quantitative, and mixed methods approach, a narrative synthesis of the results was used to analyse and report the data from the reviewed papers, and to assess the effect and role of PS groups in EI services. The synthesis of the data was undertaken by a single author (CP).

Graphical user interface

Description automatically generated with medium confidence

## Results

### Study selection

As the PRISMA flow diagram in Table 2 shows from the databases searched and once duplicates were removed, 1107 papers were retrieved. These were then searched for the presence of key words discussed above. From this, seven studies were identified as meeting the eligibility criteria. These were then hand searched for further eligible papers identified by citation searching using Google Scholar and the Staffordshire University Library. Using this method two further papers were identified bringing the total number of papers up to nine. However, as discussed previously there is a lack of research into PS in the context of EI services therefore two studies were included that did not mention ‘peer support and early intervention’ in the title or abstract but recruited from an EI service and specifically lists peer support, or a variation of PS, in its results and discussion. Two papers were excluded that had both EI and PS in the Title and Abstract but upon assessment for eligibility the papers were protocols for completing RCT’s, or evaluations or future studies and were therefore not included.

Overall quality of the articles was assessed using the tools described above and were found to be acceptable. They clearly stated a research question and selected methods that were appropriate for exploring these. Of the qualitative studies only three discussed any form of bias but this was not discussed in depth and one mixed methods study did not report their quantitative data in detail. Due to the nature of the intervention being assessed by the RCT neither of the two included had participants who were blind to the intervention they were receiving; however, steps were taken to ensure random allocation and researcher blindness.

### Study Characteristics

Of the nine studies selected for this review two were RCT’s, two were mixed methods evaluation, and five were qualitative. The studies also ranged in terms of intervention offered and the participants roles within a service. One study focused solely on the experience of PSW (Nguyen et al, 2022), two papers focused on EI staff and key stake holders perceptions of implementing and working with peer support (White et al, 2017; Hopkins et al, 2021), two looked at the impact and experience of PS for families and friends of individuals with psychosis (Day et al, 2017; Levasseur et al, 2019) and four papers focused on service users with psychosis who have accessed a form of PS (Castlelein et al, 2008; Sanderson and Richards, 2018; Blajeski and Klodnick, 2021; Kidd et al, 2021). Overall, the quality of the papers was found to be acceptable, however, the RCT by Kidd et al (2021) showed some problems in the design, randomisation and number of participants that could have led to an increase in bias which was confirmed using the RoB2.

For the quantitative data, studies ranged from using t-tests, chi-square, ANOVA and in the cases of the mixed method paired t-tests and descriptive statistics were utilised. For the qualitative studies all of them, including the qualitative aspects of the mixed methods studies, used thematic analysis to report the results of the interviews.

### Quantitative – Randomised Control Trials

An RCT by Castelein et al (2008) assessed the effectiveness of a minimally guided PS group for people with psychosis. 106 individuals took part with 50 being allocated to a waitlist condition, involving care as usual consisting of medication monitoring, psychoeducation and supportive counselling, and 56 were allocated in to closed 10-person PS groups involving 16 sessions lasting 90 minutes and taking place over 8 months. Although the study used a cut off of 9 or more sessions being attended to define good adherence from participants. The study specifically looked at the groups effect on participants social networks, social support, self-efficacy, self-esteem and quality of life. The size and content of social networks was assessed using the Personal Network Questionnaire (PQN) which looked at the frequency of contact with friends, family and other members of the PS group. Positive social interaction and discrepancies between the support people want and the support they receive was measured by the Social Support List (SSL). Self-efficacy was measured by the Mental Health Confidence Scale (MHCS) specifically measuring optimism, coping and advocacy. Self-esteem was measured using the Rosenburg Scale and quality of life was assessed using a 26 item World Health Organisation Quality of Life questionnaire (WHO QoL). The study also sought to evaluate the group both in terms of satisfaction of participants and economic impact. The results showed attending a group PS group had a positive effect on participants social network and social support, moreover, high attendance of the group had a larger impact on social support, self-efficacy and quality of life. 85% of participants reported that the intervention met their expectations and 82% reported that they felt supported by other participants. The economic evaluation revealed that there was no difference in cost between PS group interventions and treatment as usual. However, there are some limitations in the design of this study including the design not including a placebo control as participants on the wait list may have experienced improvements due to anticipation effect, also the results may not be generalisable to all populations who access EI services as all participants are clinically stable with no history of substance misuse.

An RCT by Kidd et al (2021) studied the use of a ‘welcome basket’ PS intervention to aid with transitioning from inpatient to community services for individuals with schizophrenia. 110 individuals were recruited from inpatient EI in psychosis services. The participants were randomised and allocated into one of three groups with 46 in a treatment as usual group, 41 in a full welcome basket group and 23 in a brief welcome basket group. The welcome basket consisted of one to two initial appointments pre-discharge from inpatient services followed by weekly one on one meetings with a PS worker as well as Cognitive Adaption Training (CAT) the brief welcome basket involved similar components in an abbreviated form. The primary outcome measure utilised the Multnomah Community Ability Scale (MCAS), which measures symptoms, functioning and behaviours of adults with psychiatric disabilities in the community, the data for this was assessed via participant interviews and clinician ratings. Secondary outcomes were also assessed looking at community engagement, using the Community Integration Scale (CIS); Symptomology, using the Brief Symptom Inventory (BSI); substance use, using the Substance Disorder Scale found in the GAIN-short Screener; personal recovery, with a nine item version of the Personal Recovery Outcome Measure; The frequency of social supports, assessed using the 19 item Social Support Survey and quality of life, which was measured using the Satisfaction with Life Scale. The study found that there were no significant differences between groups suggesting that PS in this instance was not beneficial to participants. However, on a 6 month follow up the participants in the treatment as usual group showed to have improved MCAS scores compared to the full welcome basket. The study itself was limited by a small sample size, metrics that were under sensitive given the short timeframe of the study and the complexity of the population being studied means that broad measures of community functioning may not capture relevant changes. Furthermore, the study may lack generalisability as it took place across only one site and participants were un-blinded to their treatment condition.

### Mixed Methods

Day et al (2017) evaluated family group interventions in an EI in psychosis program as part of a follow up 10 years after implementation. 17 participants took part in the study, these participants were recruited from those who had attended one or more sessions of the family group intervention titled ‘journey to recovery’. The intervention is a group programme facilitated by an occupational therapist and social worker, designed for family and friends of those who are currently in the EI in psychosis service. The group is held weekly for 5 continuous weeks for up to 2 hours. The group was evaluated using a pre and post intervention questionnaire consisting of 6 quantitative questions using a 4-point Likert scale, ranging from not at all good to very good, and 3 qualitative questions. The quantitative questions investigated the following areas, understanding of psychosis, understanding of recovery, knowledge of medication, felt need for self-care, relapse prevention and understanding the links between substance use and psychosis. The qualitative questions looking to capture information on other knowledge gained, other perceived benefits and opportunity to provide other feedback. The quantitative questions showed statistically significant improvements across 5 of the 6 questions with only felt need for self-care showing no significant changes. Qualitative feedback of the group was positive with themes of valuing session facilitators, reduced feelings of isolation, feelings of collective or similar experiences, appreciating an opportunity to ventilate feelings and be heard by peers who understood and increasing knowledge of participants. Although the results were positive the researchers note that critical responses were omitted from the results. The study itself was modest in size with only 17 participants and may lack generalisability as the group takes place in one service and may not be representative of the experiences of carers of those with differing or more severe psychosis presentations.

Hopkins et al (2021) looked to identify and understand the barriers and enablers to the implementation of youth PS in an EI programme. The paper evaluates the initial stages of implementing a youth PS programme with an online questionnaire that was sent to all clinical staff in the EI service. The study is unclear as to the design of the questionnaire and the number of questions asked. However, as ‘agreed’, ‘uncertain’ and ‘disagreed’ are used in the results a Likert scale can be assumed to have been used and some qualitative questions may have been asked as part of the questionnaire. 38 staff members completed the pre intervention implementation and 24 completed the 12 month follow up. The study also conducted nine semi-structured interviews with key stakeholders including youth PSW and clinical staff involved in setting up the PS intervention. The study showed that there were perceived benefits to the implementation of youth PS to both staff and service users and the intervention was feasible in its set up and design. However, significant barriers do exist that would need to be addressed including the culture of EI service teams making integrating PSW with lived experience of psychosis difficult. While staff perceptions were shown to be generally positive concerns around integration and accidentally offending PSW’s. The integration of PS required a shift in clinical practice to prevent perceived tokenism of the intervention. Limitations of this study include a small sample size and a potential lack of generalisability due to only assessing youth PS implementation in one service.

### Qualitative

A study by White et al (2017) explored the impact of PS in EI services, specifically looking at the impact that PS has on the organisation. The study used a semi structured focus group with six members of the EI service looking to take a representative sample of the Multi-Disciplinary Team (MDT). In this respect they recruited a clinical psychologist, occupational therapist, two psychiatric nurses, a social worker and a consultant psychiatrist. The focus group aimed to explore the team members experiences of working with PSW. From this focus group two main themes emerged, the first being the value of PS which also consisted of three sub themes, improving service engagement, personal qualities and the peer relationship. The second theme was the ‘peer support role’ again consisting of 3 sub themes, living experience, boundaries and alternative perspectives. The results of the study highlighted how staff valued the information and advice that PSW could offer staff as individuals with lived experience also valuing how PSW could relate to clients, encourage empowerment and reduce the impact of power dynamics. The staff also highlighted how PS is its own intervention in the service but also acts as a steppingstone for clients into other areas of the service such as therapy and can help to encourage participation and service engagement. Challenges were also identified specifically around boundaries between staff and PSW, as while PSW were employed by the service the relationship between PSW and staff differed when compared to relationships with other members of the MDT. However, the team that was interviewed had only employed PSW for a few months before the interviews took place, thus it is possible that their impact in the team was limited.

Watkins et al (2018) explored service user perceptions of an EI service. They interviewed a total of 16 service users utilising both a focus group (n=7) and individual interviews (n=9). While this study was not directly focused on the use of PSW as an intervention in EI services key themes that were reported were developing relationships with their peers which helped to facilitate recovery, enabled service users to push boundaries through talking about their concerns with other service users due to their similar experiences and also helped to normalise their experiences, encouraging connectedness with others and reducing feelings of being judged and lonely. As this study took place across one and as focus groups were also utilised it is possible that more confident service users spoke up more than others resulting in bias. Further bias may also have been present as care-coordinators referred service users into the study they may have selected service users they had a good relationship with therefore, experiences may be reported as more positive.

Levasseur et al (2018) explored the perceptions of members of a peer driven family support service run by an EI programme. The group was started initially by family members of service users with psychosis agreeing to meet for 2 hours on a weekly or fortnightly basis to allow and encourage family members to share experiences and insights about caring for an individual with psychosis. The study utilised 12 questions covering the family situation before attending the group, overall experience, meeting format and suggestions. 36 respondents were recruited from the family PS group. The key themes that were generated from the responses were, the impact of psychosis, understanding and coping with psychosis through PS and improving PS. The results suggest that family members can feel overwhelmed by supporting an individual with psychosis and felt a lack of understanding and fear for their loved one. The group provided a source of information sharing helping to alleviate some of these feelings and judgements they experienced and felt towards their loved one also helping to improve their relationships while also offering an outlet and opportunity to receive emotional support themselves. The PS group promoted emotional resilience, hope and a sense of belonging in participants which helped enhance the care and support those individuals’ experiencing psychosis received from their families. No negative feelings towards the group or barriers to accessing the group were reported. However, as identified in the study, this could have been due to the study utilising a self-report online questionnaire, therefore, the respondents may have been those who benefitted the most from the group.

In a study by Blajeski et al (2021) the influence of early stigmatising experiences, peer connections and peer spaces were explored in relation to employment and education after FEP. The study recruited 10 people who had been treated as part of an EI programme and who had also taken part in a young adult leadership council which offered a form of informal peer support. Each participant completed a two part interview the generating three key themes, ‘Hospitalisation and Psychiatric Labelling Construct Stigma’, ‘Connecting with Peers to Resolve Stigma’ and ‘Employment Connection and Peer Mentoring Through the Young Adult Leadership Council’. The results of this study showed how meeting peers helped to normalise experiences and helped to alleviate feelings of self-stigma that in turn helped improve connection and motivation towards employment and goals. However, this study is limited by a small sample size and participants were drawn from a unique environment which limits the generalisability of the study.

Individuals with an experience of providing peer support, either current or previous, were interviewed by Nguyen et al (2022) to explore PS in the context of an EI service. The study recruited 7 participants all of whom had a lived experience of psychosis and had provided peer support. 4 key themes were coded, the benefits of PS, the ideal requirements of PSW, effectively delivering PS and working alongside peers. The study also reports a central concept of the importance that PS plays in the de-stigmatisation of psychosis. The results suggest that PS can reduce stigma, provide self-management strategies, increase social support networks and reduce barriers between services and peers, motivating improved service engagement, while also providing examples of hope through modelling living well with psychosis. The paper has a small sample size and only recruited white British participants which given the over representation of psychosis among Black, Asian and Ethnic Minority (BAME) groups could limit the generalisability of this study.

## Discussion

The results from the studies being reviewed will be explored in further detail and compared to the current understanding of PS in mental health services. Several studies also discussed future directions for the implementation of PS provisions, and this will also be discussed in further detail.

A key concept that occurred throughout many of the articles involved PS facilitating a reduction in stigma felt by those who were experiencing psychosis in part by normalising and validating their experiences and feelings. Participants reported that they had felt helpless, misunderstood and fearful due to their experiences of or with psychosis (Watkins et al, 2018; Blajeski et al, 2021; Day et al, 2017; Levasseur et al, 2018). This fear was also heightened by a lack of knowledge and understanding of psychosis felt by participants (Levasseur et al, 2018). However, participants within some of the studies discussed PS as helping to alleviate some of these feelings and prevent them from feeling abnormal (Watkins et al, 2018; Blajeski et al, 2021), ashamed or judged for their experiences (Watkins et al, 2018; Levasseur et al, 2018; Nguyen et al, 2022). Some of the mechanisms behind this reduction appeared to be the benefits of being able to share experiences of psychosis with individuals and groups who have had similar experiences themselves. This shared understanding not only made participants feel accepted but also understood as they were provided with space and opportunity to offload some of their anxieties to people who they were confident would be able to understand them (Watkins et al, 2018; Day et al, 2017). One of the strengths suggested in PS within EI services is that psychosis is a condition characterised by remission and relapse and as PSWs do not just have lived experience but living experience, as their own struggles are ongoing, this models coping and further normalises experiences and offers hope (White et al, 2017). This was however, felt to be improved if the PS was delivered by or included individuals of the same demographics and with experience of similar symptom severity (Nguyen et al, 2022). This also extended to the age of participants with suggestions that older PSWs would have a different understanding of the journey through health care systems therefore limiting their understanding of service user experiences (Hopkins et al, 2020). Regardless of whether the study looked at family peer support, individual, group, or informal, the shared narrative of individuals with living experience of psychosis and the knowledge and understanding fostered and sustained in this intervention helped to reduce stigma and normalise experiences leading to acceptance.

The results of the studies are supported by the current understanding of the benefits of PS within mental health. Mental health difficulties have a history of being misunderstood and stigmatised by wider society, and this tends to increase with the severity of the mental health condition with labels such as ‘defective’, ‘dangerous’ and ‘unpredictable’ (Colizzi et al 2020). This is especially true for individuals experiencing psychosis who often elicit an increase in negative stereotyping (Yang et al, 2013). This can even be experienced in hospital settings when FEP arises and can lead to significant barriers to accessing care (Kular et al, 2018). Stigma can also be internalised leading to individuals feeling misunderstood, abnormal, and isolated from other people (Vass et al, 2017). The results from the review suggest that PS in EI services can be used as an effective method of tackling internalised stigma through normalising experiences, role modelling, acting as a symbol of hope, and creating shared narratives. However, recent research suggests these findings may not be unique to those accessing EI services, and PS interventions have shown positive benefits in terms of reduced stigma in populations with other common mental health conditions (Pyle et al, 2018; Verhaeghe et al 2008).

With the sometimes frightening symptoms of psychosis coupled with perceived stigma and self-stigma, social isolation within individuals experiencing psychosis is a common feature (Fett et al, 2022). Individuals experiencing relationship breakdowns and social isolation can have worse outcomes in treatment as well as other difficulties such as an increase in suicidal ideation (Bornheimer et al, 2020). This supported similar findings within the studies of individuals with experiences of psychosis feeling alone and isolated (Day et al, 2017; Levasseur et al, 2018; Blajeski et al, 2021). PS helped to reduce this by encouraging the development of mutual relationships and creating a sense of fellowship with their peers (Watkins et al, 2018; Blajeski et al, 2021; Day et al, 2017; Levasseur et al, 2018; Nguyen et al, 2022). The relationships developed were described as deep bonds formed through a shared understanding (Watkins et al, 2018). PS aimed to resemble meaningful interpersonal connections, usually unavailable to service users, with the intention of modelling the creation of social relationships to improve social support and connections (Nugyen et al, 2022). PS has been shown to aid in improving social skills and encouraging the formation of social relationships (Snell and Janney, 2015). These improvements in social skills and relationships are some of the key mechanisms identified as underlying the utility of PS and its association with improved outcomes and long-term efficacy (Watson, 2017)

PS went beyond just encouraging relationships. Within the family and friend PS group the results of the studies showed that by engaging with family PS the lessons and knowledge that they gained from the group helped to understand and rebuild relationships with their children also improving the communication in their relationships (Levasseur et al, 2018). PSWs also pushed service users to engage with positive risk taking especially when it came to building their social networks and relationship aiming to encourage the development of friendships outside of the PS relationships (Nguyen et al, 2022). These relational benefits associated with PS in EI services highlighted in this review is further supported by the current literature around the utility and benefits of using PS, and building these relationships is often listed in the job description of PSWs across services (Jacobson et al, 2012). The results of once of the RCT’s help to reinforce the role of PS in having an impact on service users social networks and social support, showing significant improvements after taking part in a PS group (Castelein et al, 2008) However, it is worth noting the in the RCT by Kidd et al (2021) not only were there no significant effects on relationships shown immediately after the PS intervention there was actually a significant negative impact on community functioning.

Recovery in psychosis is a complex topic predominantly due to it often being defined by periods of relapse, where symptoms can get worse due to life stresses or medication changes, and recovery. (Chan et al, 2019). It is understandable why service users can at times feel recovery impossible, intimidating, or overwhelming and it can be possible to lose motivation or be “blown away by the negativity that can come with psychosis” (Nguyen et al, 2022). The data gained from the studies share a focus on the role of PS in EI services in recovering from psychosis and also help to suggest several methods by which PS does this. One way in which this was suggested to be achieved is PS helping to demonstrate that recovery is possible and that there is hope for the future for those who are struggling, providing individuals with the strength to move forward and not give up (Levasseur et al, 2018; Hopkins et al, 2020; Nguyen et al, 2022). Not only did PS provide service users with hope but also provided a realistic but hopeful perspective on the recovery process (Nguyen et al, 2022). This can be seen as demonstrating the possibility of recovering from difficulties and provides individuals accessing the intervention a source of hope for the future and a source of information (Burke et al, 2018).

PS also aided recovery by providing practical, support, advice, and teaching coping skills (Nguyen et al, 2022; Levasseur et al, 2018). PSWs reported that they felt able to aid in recovery due to their own experiences of recovery and can guide service users around potential obstacles that they faced, as one participant stated that was the “beauty of that lived experience” being able to use their own recovery as a tool to help others (Nguyen et al, 2022). There also seemed to be a reciprocal relationship leading to feelings of fulfilment and empowerment experienced in PS, this was the case for all those taking part, whether they were PSWs themselves working with other individuals with psychosis, or service users taking part in a group (Nguyen et al, 2022; Levasseur et al, 2018).

As a peer, PSWs are often seen as being on a similar level to each other and service users, which had the effect of reducing the role that any power dynamics that may be present between service user and non-PS staff interaction (Nguyen et al 2022). PS has been suggested to help with unmet needs in individuals experiencing psychosis that may help with long term recovery in part due to encouraging empowerment through taking control of the narrative surrounding their experiences and sharing this experience with others to create a shared identity (Gillard, 2018). This shared narrative coupled with reducing power dynamics could be seen as a potential benefit to service user engagement in EI services. The PSW acts as a bridge that helps to ease service users in to the EI model of working and giving service users the opportunity to open up to individuals they see as on their level and therefore less threatening (Nguyen et al, 2022; White et al 2017). This could then be used to ease them in to working with other parts of the EI service such as psychology. This would be facilitated by PS encouraging trust to be built up between service users and staff and motivating engagement with services (Nguyen et al, 2022; White et al, 2017).

PSWs can also benefit staff by enabling them to take on new perspectives and gain insights into the service users they are working with. This was done through staff asking PSWs for their advice as to what may or may not be useful enabling them to tailor interventions to the service user (Nguyen et al, 2022). When looking at specific types of PS, PSWs can help by co-facilitating groups with staff, offering an expert by experience perspective into a psychoeducation group (Levasseur et al, 2018).

While PS in psychosis has been shown to have beneficial impacts on a number of features within the presentation and treatment of psychosis within an EI service, barriers to its implementation was noted within studies. PS roles can be confusing within teams with lack of definition leading to concerns with staff about not fully understanding the role and confusion with PSWs about what they are supposed to be doing on a day-to-day basis (White et al, 2017; Nguyen et al 2022; Hopkins et al, 2020). Conversely, some services demonstrated a rigidity in the model of PS that they offered with feelings from PSWs that they were too restricted in their roles to be able to effectively support service users (Hopkins et al, 2020). Staff also showed concerns with how effective PS would be and demonstrated a lack of confidence that service users would benefit from working with PSWs (Hopkins et al, 2020). This concern is also supported by the results from the RCT which not only showed that there were no improvements in participant outcomes immediately post-group following PS intervention, but also showed that there was a significant negative impact noted on community functioning in a six month follow up (Kidd et al, 2021). Staff were also noted to have concerns around boundaries with the PSW’s, worrying that they would not be able to talk to them like they would other members of the team and voicing concerns that they could unintentionally offend PSWs by saying the wrong thing which could lead to feelings of awkwardness (Hopkins et al, 2020; Nguyen et al, 2022; White et al, 2017). Moreover, the implementation of PS within an EI team would require a lot of effort to change the perspectives and culture of the staff teams (White et al, 2017). If the staff team within an EI does not integrate well with PSWs it risks creating an “us and them” relationship that can cause PS becoming a tokenistic offering, which may prevent PSWs from gaining adequate support from the team, potentially leading to burn out and increased distress (Nguyen et al, 2022; Hopkins et al, 2020). Furthermore, PSWs in mental health services have a history of experiencing difficult work environments with reports showing experiences of hostility and discrimination from non-peer staff as common, as well as difficulties managing boundaries and the transition from service user to peer (Walker & Bryant, 2013). This combined with common difficulties with health care staff when experiencing their own FEP could have the possibility of encouraging awkwardness and splitting within teams.

Interestingly, most staff responses included in this study were positive about the experiences of working with PS and the beneficial impacts they perceived that they would have on service users. However, this is not uncommon and could denote shifting perspectives and cultures within mental health teams towards PSWs and their beneficial effects (Ibrahim et al, 2020). Although research does demonstrate that there are multiple conflicting perspectives among non-peer staff towards PS (Kilpatrick et al, 2017).

While staff were generally positive towards PS, it is worth noting that some of the concerns that are reported in studies on PS in mental health services are also demonstrated within the results of the review. This also includes similar suggestions for how best to deal with staff uncertainty including clearly defining the role of PS within the service (Kemp & Henderson, 2012). Many of the barriers and concerns relating to the implementation of PS within EI services can be found in the implementation of PS across mental health services including uncertainty around roles, difficulty changing team cultures, feeling excluded, and staff being concerned about accidentally offending PSWs (Mutschler et al, 2022). This is reflected in the results shown in the review including concerns about PS being seen as tokenistic within the EI team.

The results discussed in this review are supported by current evidence of PS within mental health services more generally. However, there remains the difficulty of comparing PS in the context of EI in Psychosis with other services that employ PS due to the complex nature of psychosis and the sometimes challenging presentations that arise.

It is also worth noting that at least one of the studies included in this review stated that they had purposely excluded critical comments about the PS group they were researching. Further studies stated that the results of the study could have been subject to bias due to the method they chose to recruit participants, including care co-ordinators choosing participants that they felt would be more positive about their PS experiences. Bias in the papers being reviewed is also difficult to ascertain as several papers do not discuss any possibilities of bias. In one study, the primary researcher discussed their own lived experience of psychosis; however, they do not go into detail about how this could impact the study either in the analysis or recruitment phases (Levasseur et al, 2018).

### Limitations

There is limited research on the topic of PSW within an EI service for psychosis. Most of these studies reviewed reported small sample sizes and often took place not just in one service but within a specialty context, such as a youth leadership council, further limiting the generalisability of the results. Furthermore, the studies took place in multiple countries including the UK, USA, Canada, and Australia. While EI services are available in these countries, they do not all necessarily operate in the same way, or have the same demographics of service users, roles descriptions for PS and as such, variations in practice within these countries could lead to variations in experiences of the participants in the studies.

Of the four studies included in this review that looked at service user perspectives, and experiences and outcomes of PS, only three reported the ethnicity of their participants (Kidd et al, 2021; Nguyen et al, 2022; Blajeski and Klodnick, 2021) and only one of those also reported the socio-economic status of participants (Blajeski and Klodnick, 2021). Psychosis disproportionately effects those from minority ethnic (Morgan et al, 2017) and low socio economic (Fett et al, 2019) backgrounds. Therefore, it would have been beneficial for studies to record and report the demographics of their studies to help to identify and consider potential confounding variables that may also have had an impact on the results of the studies.

The studies selected for this review ranged in the type of PS that was being studied. Some of the papers included multiple types of PS being offered to participants or asked questions about PS in general not going into depth regarding the type of PS that was being delivered. The benefit of this for the purpose of the review is that PS can be looked at as a whole and the results synthesised together. However, this means that the review could not look into the specifics or differences of the experiences of different types of PS, or explore whether there are benefits to one type of PS compared with another, as well as how service users may engage with different types of PS.

### Clinical Implications

PS has been demonstrated to have range of benefits for EI services, both to service users, non-peer staff, and PSWs and this can happen with a range of possible PS pathways including more informal ones such as encouraging peer to peer contact through group attendance. PSWs were also noted to have benefits to encouraging meaningful engagement with staff and acting as a facilitator of service user and non-peer staff interactions. There is the possibility of EI services utilising PS in a way that is mutually beneficial to staff, as PSWs within EI give staff access to a wealth of experiential knowledge that they may not have access to otherwise. However, PS requires time and effort to implement and in some cases a shift in the culture of the work environment may need to take place. Careful consideration of the roles and responsibilities both of peer and non-peer staff members is also important to ensure that concerns and needs of staff and PSWs are addressed.

### Future research directions

As stated previously, there is very little research into the role and effectiveness of PS within EI services for psychosis. They are a recommended intervention with too little research to explain why this is and while the research included in this literature review would suggest that there are benefits to using PS as part of an EI in psychosis service, more research needs to be undertaken evaluating the impact of PS for people experiencing a FEP. For example, PS is suggested to improve service engagement, however, there is a lack of quantitative studies evaluating this, and an over reliance on anecdotal evidence that often does not focus on service user experiences. Furthermore, PS is suggested in research from other mental health services to aid with reducing disengagement from services. As stated previously, drop out in FEP services ranges from 12% to 53% which is exceptionally high, however, within the studies reviewed, there was no indication of how PS may impact service disengagement, and this could be explored in future research.

Finally, future research could focus on seeking to separate types of PS, whether this is a focus on one to one, group, family, or informal methods, in order to evaluate the distinct impact of each method. Finally, studies have suggested that service users would benefit from PS with individuals who are similar in age, gender, severity of symptoms, duration of illness, ethnic or cultural background, and socioeconomic status. However, currently, there are very few studies exploring the impact of ‘matching’ PSWs on a variety of dimensions, to the clients they are working with.

## Conclusion

PS can be a valuable addition to an EI service offer and can be beneficial in building relationships, tackling stigma, empowering service users, and providing staff with new perspectives and ways of working. However, there are concerns centred around the implementation of PS that would need to be carefully reviewed and reflected on, as adequate support would need to be in place for PS to be effectively utilised and maintained. Finally, more research needs to be completed into the role that PS has within EI services to ensure that they are being utilised appropriately.

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| --- | --- | --- | --- | --- | --- | --- | --- |
| Table 1. Data Extraction form | | | |  |  |  |  |
| Author/ Date/ Country | Design | N= | Measures/ Type of analysis | Type of Peer Support | Main Findings | Strengths | Limitations |
| Blajeski, Klodnick, Caruso and Sale (2021), USA | Qualitative – two part semi structured interviews | 10 Early Assessment and support alliance service users – 8 current members of the young adult leadership council and 2 former members | Thematic Analysis | The young adult leadership Informal group peer support and steering group | Early stigmatising experiences challenged participants identity and self confidence that led to disengagement from social activities. Peer support helped to normalise experiences and alleviated feelings of self-stigma. | Demographics collected  Analysis clear and rationale given  Some discussion of bias | Sample drawn from unique environment  Sample weighted heavily towards participants with more privileged socioeconomic backgrounds  Use of a focus group could create social desirability effects |
| Castelein, Bruggeman, Busschbach, Gaag, Stant, Knegtering and Wiersma (2008), The Netherlands | Randomised Control Trial | 106 participants with a diagnosis of a psychotic disorder recruited from Early intervention services    56 in guided peer support group  50 in care as usual/ wait list condition | t-test for continuous variables  Pearson chi-squared for categorical variables  Mixed model methodology for analysis of outcome measures:   * Social Support List * Mental health confidence scale * Rosenburg scale * WHO Quality of Life * Personal network questionnaire | Guided Peer support group | The guided peer support group showed significant positive effects on social network and social support compared to the control condition  In the experimental condition high attendance predicted increased social support, self-efficacy and quality of life. | Used logistic regression to determine if age, gender, duration of illness, psychotic episodes, severity of psychopathology, peer contact, self-esteem and treatment location were predictors of positive outcomes  Researchers blind to intervention status of participants | Participants not blind to treatment condition |
| Day, Starbuck and Petrakis (2017); Australia | Mixed Methods – Questionnaire pre and post intervention | 17 family and friends of individuals with psychosis invited to take part in a psychoeducation group | Online questionnaire  Containing 9 questions  Quantitative  Paired t-tests  6 questions utilising a 4-point Likert scale  Qualitative  thematic analysis  3 questions at the end of the questionnaire | Family peer support group – facilitated by two early psychosis senior clinicians, an occupational therapist and a social worker | Statistically significant improvements in understanding of psychosis, recovery, relapse prevention, and substance use. With qualitative responses demonstrating participants perceived value in peer support that reduces isolation and stigma. | Demographic details recorded | Small sample size  Limited to one group  Limited information on how thematic coding took place  No discussion of bias  Results not reported in detail |
| Hopkins, Pedwell, Wilson and Howell-Jay (2021), Australia | Quantitative - Survey  Qualitative – semi-structured interviews | 38 members of staff initially completed a pre-survey and 24 staff completed a post survey 12 months after peer support implementation  9 semi-structured interviews with key stakeholders including peer support workers and staff involved in setting up the intervention | Quantitative – Descriptive statistics  Qualitative – Thematic Analysis | One to one and group peer support | The study found that it is possible and beneficial to implement a youth peer support programme. However, found barriers in the form of lack of appropriate training, lack of confidence from staff and concerns from staff over boundaries with Peer support workers and integrating them in to the team. | Good reporting of qualitative results  Methods given good rationale | Data collection not reported in detail  Descriptive statistics only  Dropouts not accounted for in data analysis |
| Kidd, Mutschler, Lichtenstein, Yan, Virdee, Blair, Mihalakakos, McKinney, Collins, Guimond, George, Davidson, Velligan and Voineskos (2020), Canada | Randomised Control Trial | 110 participants with a diagnosis of psychosis recruited from early intervention inpatient ward  46 – treatment as usual  41 – Full ‘Welcome Basket’  23 – Brief ‘Welcome Basket’ | ANOVA  Primary outcome measure   * Multnomah Community Ability Scale   Secondary outcome measures   * Community integration scale * Brief Symptom Inventory * Substance disorder Subscale * Personal recovery outcome measure * Social Support Survey * Satisfaction with life scale | ‘Welcome Basket’ – peer support delivered transitional intervention included one to one and group intervention | No significant differences in either brief or full ‘welcome basket’ interventions compared to treatment as usual across any measure.  After 6 month follow up Multnomah Community Ability Scale showed significant difference with treatment as usual having better outcomes comparerd to full ‘welcome basket’. | Dropouts accounted for in the analysis of results. | Small sample size due to splitting participants across 3 groups  no demographic information captured  study was not blind to participants |
| Levasseur, Ferrari, McIlwaine and Lyer (2018), Canada | Qualitative – Open ended questions in questionnaire | 36 – Attendees of support meetings | Thematic Analysis | Family Peer Support Groups (for carers of people with First Episode Psychosis) | Family members received support through sharing experiences and providing an understanding, supportive, empathetic and informative environment. | Some demographic details captured  Data analysis reported thoroughly  Some discussion of bias  Collaboration with families on questionnaire creation | Data collected by online self-report possibility that only individuals with positive experiences would respond |
| Nguyen, Goldsmith, Rains and Gillard  (2022); UK | Qualitative – Individual Semi Structured Interview | 7 – Peer Support Workers | Thematic Analysis | Peer support Group  online  one to one | De-stigmatisation was a central concept that was present throughout themes and participants saw peer support as a meaningful source of support, hope and aided in building relationships with non-peer staff. | Demographic details captured and reported  themes returned to participants for validation  results reported in detail | Relatively small sample size but not unusual for qualitative  Participants all white British    No discussion of bias |
| Watkins, Sanderson and Richards (2018), UK | Qualitative – Individual interviews and focus group | 16 service users of an EI service 9 individual interviews  7 focus group | Thematic Analysis | Informal Peer Support as part of a group | Relationships with other service users highlighted as important due to normalising and validating experiences with psychosis. | Themes developed independently by researchers initially then compared  Some discussion of bias from researcher being white male | Small sample size  Care co-ordinators may have selected participants that they had a positive relationship with |
| White, Price and Barker (2017), UK | Qualitative – Focus group | 6 – EI MDT members | Thematic Analysis | Unknown | Findings imply that the implementation of peer support in early intervention improved service engagement and facilitated better relationships between service users and staff which could aid in producing better outcomes. | Good representative sample of Early Intervention Multidisciplinary Team  Codes reviewed by team  Robust reporting | Small sample size  The peer support worker in the team had only been employed for 6 months at time of interview |

# Paper 2: Empirical Paper

## Positive Changes Following an Experience of Psychosis: A Grounded Theory Exploration

Word Count – 7,902

*Formatting note: This paper has been written in a style outlined by the journal ‘Psychosis: Psychological, Social and Integrative Approaches’ which has been identified as an appropriate publisher (see Appendix 1 for style guidelines/ formatting template). For the purpose of academic assignment some guidance has not been followed which will be changed or removed when submitting for publication.*

## Abstract

**Introduction**

There has been an increasing focus in research into positive changes that occur following an experience of psychosis (Jordan et al, 2018; Slade et al, 2019; Jordan et al, 2020; Ng et al, 2021). Positive changes is a term used to describe long lasting positive after effects of challenging experiences such as mental health difficulties, whereby individuals experiencing these difficulties move beyond the base line functioning that they had previously. There are, however, relatively few studies directly looking at how individuals with psychosis understand these changes. Therefore, this research aims to explore the understanding and perceptions of individuals who identify as experiencing positive changes as a direct result of an experience of psychosis to answer the following questions:

1. How do individuals with an experience of psychosis understand positive changes that may have occurred due to their experience?
2. What is the mechanism for facilitating these positive changes?

**Methods**

This research takes a critical realist perspective and utilises a Straussian Grounded Theory approach to help to analyse data and create an emergent theory to help explore and meet its aims. Participants were individuals who identified as experiencing positive changes in their lives that they credit to their experience of psychosis. They were recruited through the use of social media sites (Twitter, Facebook, Instagram, Reddit and LinkedIn) and data saturation was reached after eight interviews.

**Results**

From the analysis of the participant interviews and subsequent cross comparisons five key categories, with associated subcategories, emerged, ‘Psychosis Experience’, ‘Initial Perceptions of Psychosis Experience’, ‘Internal and External Catalyst for Change’ ‘Positive Changes’ and ‘Maintenance of Positive Changes’. This then helped to develop an emergent theory and explanatory model to help explain the generative mechanisms.

**Discussion**

The majority of the results found during the analysis have been supported by the current literature, however, there are elements of the categories and subcategories that are less reported including the ‘pleasant/comforting’ aspects of the psychosis experience or the idea that positive changes may help to maintain themselves.

**Conclusion**

This research provides novel insight into the experience of psychosis and the positive changes that can occur. It is important to note that psychosis is a complex topic and the meaning and sense making that individuals have about their experience of psychosis can be incredibly varied and unique to the individual. The results help to provide further evidence in support of the phenomena of positive changes while also helping to consider potential generative mechanisms by which positive changes are facilitated and maintained.

## Introduction

### What Is Psychosis?

Psychosis refers to a collection of symptoms that affects the way an individual perceives and interprets reality (National Institute of Mental Health, 2023). While the defining characteristics of psychosis have largely remained unchanged for over 100 years (Heckers, 2011), there have been repeated revisions to the classification by both the American Psychiatric Association (APA), in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), and the World Health Organisation (WHO), in the International Classification of Diseases (ICD-11). However, generally for a diagnosis of psychosis to occur a number of symptoms must be present, these are usually split into the terms positive and negative. Positive symptoms refer to those that add to or distort an individual’s functioning such as delusions (fixed false beliefs), hallucinations, disorganised speech, thoughts and behaviour. Negative symptoms refer to those that involve a reduction or loss of functioning, such as restricted emotional expression, vocal flattening, alogia (reduced speech) and a lack of motivation (APA, 2013; WHO, 2019).

There is no one cause of psychosis and can be the result of a combination of various factors including genetic risk, differences in development, exposure to stressors and may also form part of a physical or mental health difficulty (National Institute of Mental Health, 2023). Therefore, the global prevalence of psychosis is difficult to accurately assess due to a number of factors including variations in reporting and recording of the number of individuals affected by psychosis as well as variations in exposure to potential causes of psychosis including environmental factors, genetics and exposure to risk factors (Moreno-Küstner, Martin & Pastor, 2018). However, in the UK psychosis is believed to effect 0.7% of individuals aged 16 and over (Public Health England, 2016).

### The Experience of Psychosis

The impact of psychosis itself is well-researched, with most studies focusing on the distressing and harmful aspects of psychosis and the negative effects that this may have on an individual’s life. Studies have focused on cognitive impairments, including poorer memory and inattention (Cuesta et al, 2012) and social deficits such as reduced emotional processing, poorer social awareness and increased social isolation (Birchwood et al, 2007). Current research has also focused on the distress that psychosis may elicit such as the anxiety and fear that hallucinations and delusions may cause (Fusar-Poli et al, 2022). The treatment of psychosis can be highly distressing due to instances of involuntary hospitalisation, forced medication as well as seclusion and restraint, which can be significantly traumatic at times inducing symptoms that are associated with Post Traumatic Stress Disorder (PTSD) (Berry et al, 2013; Dunkley et al, 2015; Rodrigues & Anderson, 2017)

However, psychosis is a complex topic and while there are a number of studies that highlight the difficult and distressing elements of the experience there has been a growing interest in positive and comforting aspects of the psychosis experience. With some studies highlighting hallucinations, in particular voices, as providing safety and protection, guidance, offering companionship, supporting psychological and emotional wellbeing and facilitating personal growth in individuals experiencing psychosis (Valvanis, Thompson and Murray, 2019).

### Positive Changes Following Psychosis

An area of increased interest has been into the positive changes that can occur following an experience of psychosis (Jordan et al, 2018). Due to psychosis being linked to trauma and PTSD this has also been conceptualised in the same category as the theory of Post Traumatic Growth (PTG) or stress-related growth (Ng et al, 2021). The general principle linking these terms is that following an experience of psychosis, long lasting positive changes can occur for individuals (Ng et al, 2021). The positive changes that have been seen to most commonly occur following an experience of psychosis are stronger sense of self and personal identity (Jordan, Malla & Iyer, 2017; Friesen, Goldstein & Dixon, 2021) improved relationships, spirituality, resiliency and emotional experience (Ng et al, 2021).

While there has been an increased interest into research on this topic there is still a relative scarcity of studies focusing on the lived experience of psychosis, long lasting positive changes, the understanding individuals may have of this experience and why it may have occurred.

This research primarily focuses on positive aspects of psychosis and does not exclusively identify the experience of psychosis as inherently or purely distressing or traumatic. Therefore, the term used when describing long-term positive outcomes elicited from an experience of psychosis, that will be used throughout this paper will be ‘positive changes’ instead of PTG or other distress related models.

## Aims and Research Question

The aim of the research is to explore and understand the lived experience of positive changes from the perspective of individuals with an experience of psychosis. The research, therefore, is looking to answer the following questions:

1. How do individuals with an experience of psychosis understand positive changes that may have occurred due to their experience?
2. What is the mechanism for facilitating these positive changes?

The main objective of the research is to develop an explanatory model of how individuals understand and conceptualise their positive changes and how they believe these positive changes have occurred.

## Methodology

### Epistemological Position

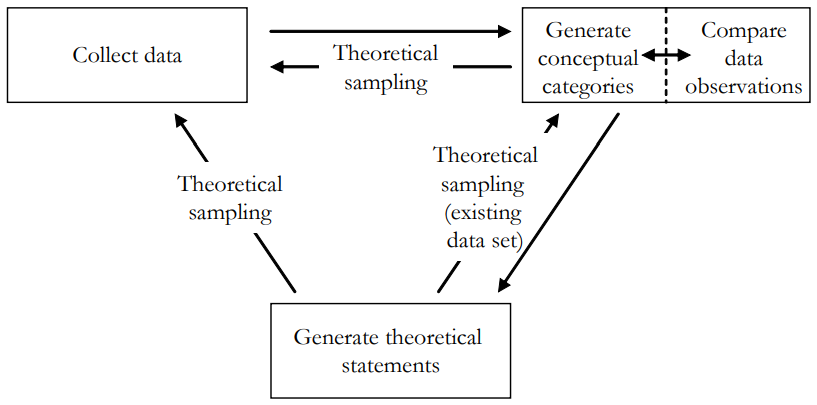
For the purpose of this research a Critical Realist position was held. Critical Realism, first founded by Bhaskar (1978) posits that an objective reality exists independently of thoughts and the discovery of this reality is one of the functions of knowledge acquisition, the position also identifies that reality is experienced through perception and that all experiential phenomena can be explained by underlying generative mechanisms. Therefore, by adopting a Critical Realist position, the research sought an explanation that linked events and experiences to generative mechanisms (Oliver, 2012).

### Grounded Theory

This study utilised a grounded theory approach to explore and analyse participant experiences to aid with the development of an emergent theory grounded in the experience itself. Grounded theory (Glaser & Strauss, 1967) is a commonly utilised qualitative methodology that is mostly utilised when a phenomena has no existing theory or is under researched, as is the case with positive changes in psychosis. There are numerous types that share some core characteristics. Namely, not testing or confirming hypothesis, simultaneous data collection and analysis, employing constant comparisons, utilising memo writing to refine and develop categories, and use of purposive sampling for theory construction and refinement (Oliver, 2012). Grounded theory also utilises diagramming to help to demonstrate relationships, clarify analysis and illustrate ideas and the emergent theory (Charmaz, 2006). This will also be utilised within this research and discussed below.

The method of grounded theory utilised in this research was modelled after the Straussian model (Strauss and Corbin, 1997). The decision to follow a Straussian methodology was made due to the research having clear aims and research questions and due to the epistemological stance of critical realism requiring an initial understanding of the objective reality of positive changes, achieved through a review of the existing literature.

**Figure 1**

*Straussian Grounded Theory’s Recursive Analytic Operations*

Note. The figure above shows Straussian Grounded Theory’s Recursive analytic process of data collection (Thai et al, 2012) which was used in this study. The figure shows how analysis followed a process of initial coding, comparative analysis and theoretical sampling until saturation. *Figure 1*. illustrates that for Straussian grounded theory the data collected and theory generated must be constantly compared and contrasted. This process helped to direct ongoing data collection and the questions that participants were asked. The Critical Realist stance, discussed above, was held throughout.

### Ethics

Due to this research not involving participants recruited through the National Health Service (NHS), ethical approval was gained through Staffordshire University’s ethics review panel and research activities were overseen by an academic supervisor and followed the British Psychological Society’s Code of Human Research Ethics (2014).

### Participants and Recruitment

Participants of this research were individuals who identify as having had an experience of psychosis who believe that due to this experience they have acquired long lasting positive changes in their lives. The participants had to be over the age of 18 to ensure that informed consent could be gained but no upper age limit was implemented. Participants were also required to not be experiencing acute symptoms or suicidal ideation at the time of recruitment in order to be eligible.

Participants were recruited through the use of social media; specifically, Twitter, Facebook, Instagram, Reddit and LinkedIn. This was primarily done through the use of a poster (Appendix 2) and hashtags to aid with targeting specific groups, i.e. psychosis and positive psychosis recovery. Once initial contact was made, participants were screened for eligibility for the study through the use of an information sheet and consent form (Appendix 3 – 4).

Nine participants were recruited, all of whom identified as having experienced positive changes as a result of their experience of psychosis and consented to take part in the research. Eight of those participants who completed the consent forms took part in the interview with one participant not attending their interview.

Demographic details were not collected from participants as they are not deemed necessary for research utilising grounded theory, as sampling methods focus on specific concepts and incidents, in the case of this research the concepts were ‘psychosis’ and ‘positive changes’ (Corbin and Strauss, 1990; LaRossa, 2005, Teppo, 2015). Furthermore, in the case of psychosis, collecting demographic details could have presented a barrier to individuals engaging with research, therefore, making it harder for lesser heard voices to access and take part in the research which could hinder theoretical sampling (Woodall et al, 2010). However, within interviews participants discussed their backgrounds, age, gender and occupations and where relevant these will be discussed.

### Data Collection and Analysis

Data collection was completed using unstructured interviews, as set out in Grounded Theory models the first interview began with broad open questions designed to provide an overview of experiences (examples in Appendix 6). Participant interviews lasted between 40 – 60 minutes and took place via Microsoft Teams (MS Teams), either utilising video or audio only recordings, with no participants opting for phone call interviews. Consent forms were completed digitally (Appendix 4) via Staffordshire University’s Qualtrics platform and all participants were provided with an information sheet (Appendix 3) and opportunities to ask questions about the research before interviews began. Immediately following the interview participants were offered an opportunity for debriefing and were sent an electronic copy of the debrief form (Appendix 5). Participants were reminded of their right to withdraw their data and the limits to withdrawal (as their data forms the basis of subsequent interviews and initial analysis takes place before the next interview data extraction cannot be guaranteed after two weeks post interview once the following interview has occurred). Six participants opted to be contacted following their interview once the emergent theory had been sufficiently developed.

Interviews were transcribed automatically via MS Teams; the transcript was then anonymised by the alteration or removal of personal identifiable data, participants were assigned pseudonyms to aid with anonymity and any errors in transcription were removed. Transcripts were initially printed to aid with initial open coding to inform the emerging theory and direction of subsequent interviews (example transcript and coding Appendix 7.1 and 7.2). Memo notes aided with the analysis by capturing reflections and rationale for emergent theory (example in Appendix 8).

Following Straussian Grounded Theory Principles, the initial analysis of transcripts followed the guidelines of open coding to identify emergent themes, followed by axial coding and then selective coding as the theory developed. Number of participants was dictated by data saturation, with saturation being the point at which no new codes or themes could be acquired through further interviews (Vasileiou et al, 2018).

The theory developed also underwent a further validation process achieved through participant feedback, whereby the emergent theory and supporting quotes were sent to participants that had opted into being contacted post interview to discuss results and analysis. Participants were offered the opportunity to provide feedback and share divergent views. The additional consultation supported the emergent theory and therefore no changes were made.

### Reflexivity and Retroductive Reasoning

The study utilised a reflective log (example in Appendix 9) to aid with researcher reflexivity. Reflexivity is an essential tool for researchers when conducting qualitative research predominantly due to the emphasis on subjective interpretation of the data and inherit bias that researchers may hold and can aid with facilitating understanding both of the phenomena being studied and the processes involved (Watt, 2007).

Furthermore, due to the epistemological stance of the research, i.e. Critical Realist, the process of retroductive reasoning was employed which utilised reflexivity and current knowledge to aid with developing a theory on generative mechanisms based on the observations and data present (Oliver, 2012).

## Results

The final categories developed from the grounded theory approach are presented below, to ensure conciseness of the research individual codes and previous conceptualisations of the model and any previous categories are not given instead focusing on the final model and themes developed. The results of the analysis highlight five distinct categories with associated sub-categories. These categories are ‘Psychosis Experience’, ‘Initial Perceptions of Psychosis Experience’, ‘Positive Changes’, ‘Internal and External Catalyst for Change’ and ‘Maintenance of Positive Changes’. These categories and sub-categories are discussed in more detail below.

### Psychosis Experience

The category ‘Psychosis Experience’ was developed through the analysis of each participant interview and then subsequent cross comparisons which uncovered three sub-categories. This category aimed to conceptualise the participant’s experiences of psychosis symptoms. One of the important features of this category is the variation of each participant’s experiences, however, despite these variations shared sense making existed between participants. Sub-categories for this category were *‘Difficult/Unpleasant’,* ‘*Pleasant/Comforting’* and ‘*Neutral’.*

#### Difficult/Unpleasant

When asked to describe their experience of psychosis several participants made reference to ‘*Difficult/Unpleasant*’ experiences that they had due to the symptoms that they were dealing with. In reference to their hallucinations participants noted aspects that they struggled with symptoms such as tactile hallucinations of “bugs crawling under my skin, worms in my spine and my brain” (Miranda), visual hallucinations of “a woman… all dressed in black and she was poking the knife through the mail slot to get at me” (Sarah) and auditory hallucinations where by a participant would “hear them talk about me and how I'm not doing anything about it, and that I'm waste of space”. Other participants would discuss the emotional difficulties that these experiences were having on them finding that their experiences “could be very embarrassing” (Helen). Embarrassment, in particular, was mentioned a number of times by participants with one stating that despite living with psychosis for a long time they “Still feel really embarrassed” (Fiona). Participants also disclosed feeling “anxiety” (Miranda), “fear” (Victoria) and “Rage” (Oliver).

#### Pleasant/Comforting

Participants also discussed how there were elements of their psychosis symptoms that they perceived as *‘Pleasant/Comforting’* at times offering support during particularly difficult experiences. Sarah, for example, discussed how “my delusions were my coping mechanism” and that “it would give me a break from. The terror and the fear. Because I can go into this magical world and that was a place of safety for me”. Psychosis symptoms were seen as an additional coping mechanism or a sign that they needed to take care of themselves “The hallucinations, as a warning sign for when you're becoming overstressed” (Victoria). The psychosis experience also helped to cope with other difficult experiences “anxiety about everything melts away” (Luke).

“she's a very large, probably, 2 and 1/2 feet high, fluffy grey cat, with very pale eyes and what's really totally wild about this hallucination is that she blinks very slowly at me, and it's always been very comforting” (Miranda)

#### Neutral

Alongside ‘*Pleasant/Comforting*’ and ‘*Difficult/Unpleasant*’ experiences participants also noted that some of their experiences conformed to neither and were instead more ‘*neutral’* providing neither comfort or distress. Stating that some experiences “started off neutral” and “Not threatening” (Victoria) and while the experience may still be “an intense experience” (Luke) it is not necessarily positive or negative. This can also be seen in the hallucinations that individuals experience whereby they are “Just sounds” or “people talking, but not usually to me” (Miranda)

“I see my hallucinations almost, like, neutral…. like if you've just got like a problematic old relative who says crap but know they’re a bit odd but you love them anyway” (Victoria)

Participants were however noted as stating that attempting to categorise their experiences as wholly ‘*Difficult/Unpleasant’*, ‘*Pleasant/Comforting’* or ‘*Neutral’* was not possible as there were times when their psychosis presentation could encompass all of those experiences at the same time. Describing events as “Magical in a way but… also quite scary” (Sarah) with one participant making note that when trying to understand the experience of psychosis it is not as easy as “simplifying and categorising the experience as an entirely negative or bad thing or an entirely positive thing” (Luke) and that many of their experiences while scary would also help them to feel comforted.

### Initial Perceptions of Psychosis Experience

Participants reflected on their initial perceptions of the experience of psychosis there was a large variation in the initial experience however through cross comparison emergent sub-categories were discovered, namely the experience of ‘*Loss’* and ‘*Stigma’*. These two sub-categories were kept purposely broad to demonstrate how varied these experiences can be.

#### Loss

The sub-category of ‘*Loss*’ describes how participants felt that they lost certain aspects of their lives this was both personal and interpersonal. This wider category of loss is characterised by participants noting a loss of identity/sense of self, in that participants felt that “my whole identity had been stripped away from me” (Sarah), and “Your sense of self kind of melts away” (Luke), “I felt like it stole my identity” (Miranda). Participants also noted loss in their relationships, “I would be unreliable in relationships” (Oliver) also noting that it could also be difficult to “make relationships” (Helen). Loss of social life, this could be due to a number of factors including reflecting that they “start to withdraw or…. lose social functioning” (Helen) which would lead to “I would isolate myself quite a lot” (Helen) and that the “energy of psychosis scares people so they want to stay away from you and you experience a lot of isolation” (Sarah). Loss of confidence “It's harder to trust my thoughts and beliefs now” (Sapphire).

“I went through grieving, for all my losses” (Sarah)

#### Stigma

Participants also noted on the stigma that they felt towards psychosis as an experience, this was categorised by the concepts of both stigma from others and self-stigma. The stigma from others was noted by several participants either through their direct interactions with others, one participant noted that they were told by a romantic partner that “you can't stay the night because I'm afraid you're going to kill me in your sleep” (Sapphire), “everybody's saying oh they're dangerous and they're violent and they're abusive” (Sarah) and one participant noted being asked regarding psychosis “how do you tell who are the dangerous ones?” (Victoria)

Self-stigma came in a number of different ways including how they perceived how psychosis affected their interactions with others “hard not to in some ways, internalise some of that stuff” (Sapphire). This led to a number of participants attempting to hide that they experienced psychosis from others, such as, “I never told his family because I didn't think that they would get it I thought that they would treat me differently” (Miranda). Helen similarly voiced that they “thought I had to protect myself from that for a very long time. So probably … I wouldn't have spoken like this at all” so that they wouldn’t “scare anyone with my story or … make things awkward”. One participant similarly noted that they “didn't want to be a burden” (Fiona) in their relationships. Finally Luke noted that he judged himself for struggling with psychosis, asking “how come I haven't conquered this? What I am is lesser than I could be, why do I judge myself so harshly like that?”.

### Positive Changes

Participants identified a number of ‘*Positive Changes’* that they believed occurred as a direct result of their overall experience with psychosis, the subcategories being, improvements with ‘*Empathy’, ‘Resiliency’, ‘Self-Identity’, ‘Advocacy/ Career’, ‘Stronger Personal Relationships’, ‘Social Life’* and a ‘*Greater Appreciation for Life’* these are discussed in more detail below.

#### Empathy

All eight participants discussed their belief that following their experience of psychosis they had greater empathy and compassion for those around them, “all that suffering… it's really made me have a lot of empathy for people.” (Sarah), “There is more understanding, there's more empathy” (Miranda), “this really like difficult experience has made me more compassionate and empathic” (Helen), “Being empathic and kind to people” (Luke). It is possible that increased empathy has been generated though suffering and having a difficult experience that has made those with psychosis more aware of other people needs.

#### Resiliency

Due to the sometimes challenging experience of psychosis participants voiced feeling as though they were able to cope better with other challenging situations. “it's taught me to handle life better like that. Ups and downs. There's not too much that phases me” (Sarah), “knowing that I've had that experience It didn't kill me” (Fiona), “I definitely feel that resilience” (Sapphire), “I know that I can get, go to the depths… and come and come back from it” (Oliver)

#### Self-Identity

One of the initial perceptions of the experience of psychosis was a loss of self/ identity, however following on from the experience participants noted that they felt that their sense of self and their self-identity changed for the better with Sarah noting a “Complete transformation of myself” and Sapphire noting that the experience “has given me a positive identity”. Some of this positive change around identity came from being able to recognise that “I have my own identity and I can live with psychosis and not be the girl with psychosis” (Miranda). Similarly, Luke recognised that psychosis was a “part of my history and my experience, but not as my identity I think that's a healthy thing you shouldn't be defined by… any label” but that the experienced “has helped me shape my identity” (Luke)

#### Advocacy/ Career

Due to their experience with psychosis many participants noted that they had become more active in their advocacy for those struggling with their mental health or with psychosis with rationalising that their experience of psychosis caused them to feel that “when I have the opportunity to do something good I do it… because if it can help, just one person, won't you feel like that's made your experience worth it?” (Fiona). Sapphire helps to run an online support group aiming to combat the isolation that individuals experiencing psychosis can have stating they developed a “passion and drive for improving things for myself and others” and wanted to “take my experiences and relate them to people who have similar experiences and combat some of the loneliness and isolation”. Sarah wrote a book about her experience because she “wanted to share my experience to empower people”. Several participants also credit their career choices to their experiences, Helen for example originally quit her job to focus on recovery before joining an Early Intervention (EI) service as a peer support worker. Similarly, Luke and Oliver began careers in Mental health work, “I kind of credit like almost… all of my successes down to that experience, and that the fact that I'm here on the on the Clinical Psychology course” (Oliver) finding that “there's a legitimising aspect of working in mental health when you when you know what it's like” (Luke). Both Victoria and Miranda pursued careers in research and advocacy after their experience of psychosis helped them “discover that mental health was something you could research” (Victoria) which had a “a major impact on my career and a positive one” (Miranda).

#### Stronger Personal Relationships

As stated previously participants felt that they lost relationships due to their initial experiences of psychosis, however, they reflected that following on from this the personal relationships that they formed after their experience of psychosis were stronger because of this. Participants suggested that one reason for this was that they actively sought out different relationships “I seek deeper, meaningful Connections” (Oliver), “I found people who I really trusted…people who I felt would really stick by me and would really be strong, true friends” (Miranda). These relationships were seen to be “more resilient than other relationships” and “longer lasting” (Sapphire). Participants still made reference to the relationships they lost with Victoria stating they “don't have as many of them, but I think what I do have is good quality” and that “now all my relationships that I have they're authentic” and “meaningful” (Sarah). Several participants noted being more selective with Luke asking himself “who am I giving my time to? Who do I choose to open up to and be close with?”

#### Social Life

Improvements in ‘*Social Life’* was kept separate from ‘*Stronger Personal Relationships’* to encompass the wider social networks, community and support those participants built following their experience of psychosis. Despite some initial difficulties with forming social connections participants noted that they felt “able to connect better with other people” (Fiona). The experience of psychosis enabled participants “to find people who were willing to really be there for me” (Miranda). The participants described finding social groups both in person and online that were able to provide support them.

#### Greater Appreciation of Life

The final positive change that was discovered through the interviews was that participants felt a greater appreciation for their lives post psychosis experience. Sarah noted that she was *“*totally planted in the here and now” which was echoed by Fiona who stated that she was ‘at a point now where I'm not just in survival mode’ and therefore could focus on the here and now and the positive of her life. “It has really deepened my gratitude and my sense of accomplishment” (Miranda). Crediting the experience as “clarifying what and who is really important in your life” and helping them “maintain perspective on a day-to-day basis” (Luke).

### Internal/ External Catalyst for Change

When discussing the causes of the *‘Positive Changes’* that the participants experienced participants noted a number of different factors that contributed to this, while there was a lot of variation between participants when comparing participant responses these causes could be split into external factors such as the support that they received and internal factors such as reflections that they made.

#### Internal catalysts

Participants personal experiences and values impacted the way in which they viewed their psychosis experiences “I think having that really deep understanding of myself and being able to recognise my experiences made it easier for me to process” (Miranda). As well as the agency they felt that they had “I think by being able to advocate for myself, it's really been a catalyst for the positive change and understanding” (Miranda). Participants also mentioned that their own ability to reflect on their experiences and try and make sense of their experience asking “What does it mean to you?... ultimately that determines how you're going to feel about it later on” (Fiona) this helped to develop the belief that “I think I can get better” (Helen). This confidence also enabled participants to feel able to “talk[ing] about my story and kind of open[ing] up to people” (Luke) which helped to encourage ‘*Positive Changes’*. Several participants also noted that it wasn’t until they experienced feeling as though they were “hitting rock bottom… I didn't have much else to lose” (Victoria) that they had a “wake up call” (Fiona) giving them the resolve to engage in the actively trying to make positive changes in their lives “only choice is to try to fight and continue being independent” (Sapphire). Finally, participants also discussed needing to have the ability to “to utilise those opportunities” (Oliver) and support that was offered.

#### External Catalysts

Participants also discussed and reflected how they believed that there were external factors that supported with the production of positive changes in their lives. This could be further broken down into further subcategories of ‘*Professional Support’* and ‘*Social Support’*. Oliver, in particular, reflected on the role of professional support in the creation of positive changes stating, “I'd credit a lot of it down to down to the EI team particularly… they encourage those positive changes”. An aspect of the professional support that they found particularly beneficial was “The person centred nature of the of the clinician's absolutely… the gentle manner with which they spoke… the questions they asked that allowed me to reflect” (Oliver). This was similarly voiced by several other participants, such as Miranda, who had accessed therapeutic interventions “therapy… helps me work through a lot of the whys… how’s… and the what do I do’s?... working through it on that emotional level has made a big difference”. However, it is worth noting that even for those participants with mainly positive experiences of mental health services there were also those who had negative or mixed experiences “I’ve seen a few different psychiatrists. Not all of them good” (Miranda) and describing experiences of health care systems as “not good, but I think it's perhaps the nature of the first interaction” (Victoria).

Potentially bridging the gap between professional support and social support seemed to be the role of Peer Support with Helen stating that for her “Peer support was really important”, whether this was informal or formal with Sapphire stating that “finding people who are like me… helped develop a better worldview and a better desire to help others” (Sapphire), and Miranda stating that having “friends who also have experiences with psychosis is a whole new level of support…having people who kind of understand” highlighting the importance of this when considering that positive changes and recovery is even possible.

Participants also discussed the role of social support, specifically their close relationships, family and close friends, who helped to support them and credited this to acting as a catalyst for the ‘*Positive Changes*’ that they have experiences, “I've had a very strong support system of friends and family” (Miranda), “my family has never abandoned me. My family has shown up for me” (Luke). These support systems helped participants develop coping strategies that aided with positive changes, such as Sapphire noting that they can “have difficulty with insight, and I've developed a support system to be able to help me even when there's that lack of anxiety”.

A final external factor that is also important to take note of is the importance that time played in helping develop positive changes. With participants noting that “I healed on my own. I didn't have any help it was just the right timing” (Sarah) or they put their positive changes down to factors such as luck with one participant stating that they were “just lucky... in that time and place” (Oliver).

### Maintenance of Positive Changes

The final category that has been discovered through the interviews is what participants feel helps to maintain the positive changes to ensure that they are long lasting. Several noted that their close family, partners and children were enormously helpful when attempting to maintain positive changes as they were “accountable to more people than just myself” (Luke) which gave them motivation to maintain routines and coping strategies such as “Physical activity like exercise, my diet” (Luke) and continuing to take part in “therapy once a week” (Fiona). The idea that the *‘Positive Changes’* themselves helped to maintain each other was also discovered “I've got a taste now of how things can be better for me, and I also know the hell that I went through” (Fiona). A specific example of this was given by Miranda who noted that it was “finding my passion and advocacy… helped make the positive changes stronger and has helped them stick around because I continuously have more reinforcing experiences”. This is potentially best summed up by Victoria who described “an upward cycle of positive effects” whereby the positive changes encouraged further positive changes and helped to maintain each other.

## Figure 2.

## Emergent Theory Diagram

Maintenance of Positive Changes

Internal/ External Catalyst for Change

Figure 2. illustrates the links between the categories and sub-categories that have been generated though this research with arrows helping to direct how the individual is theorised to move from the initial ‘*Psychosis Experience’* towards ‘*Positive Changes’*. Therefore, the ‘*Psychosis Experience’* is shown at the top of the model with the ‘*Initial Perceptions of Psychosis’*, these experiences and perceptions continue until the introduction of an ‘*Internal/ External Catalyst for Change’* which helps to both generate and maintain *‘Positive Changes’*. Continuing with the Critical Realist stance the main generative mechanisms for positive changes are shown on the graph as the ‘*Psychosis Experience*’ itself, the ‘*Internal/ External Catalyst for Change’*, with ‘*Maintenan*c*e of Positive Changes*’ factors being shown to be influenced by the *‘Internal/ External Catalysts for Change*’ and connected to the *‘Positive Changes’* which are shown to be connected to aid with demonstrating how they can help to maintain themselves.

## Discussion

### Emergent Theory and Links to Current Literature

Initially it is prudent to discuss how the emergent theory created through the use of GT analysis is supported by the current literature before moving on to novel or lesser researched elements that may have arisen. To do this the categories and subcategories generated will be compared to the current understanding of psychosis and positive changes.

To begin, it would be worth looking at the *‘Experience of Psychosis’* and perceived consequences of this experience, essentially the context of the participants and how they began to make sense of what was occurring for them. As stated previously research into the experience of psychosis and its symptoms has predominantly focused on the unpleasant or traumatic aspects of it. Even in research specifically focused on positive change the term “suffering” is used to describe the core experience of psychosis itself (Jordan et al, 2018). From the experiences of psychosis that the participants reflected on within this research, suffering and dealing with the difficult experiences of psychosis is certainly a common feature within the initial experience and is shown in the subcategories of ‘*Unpleasant/Scary’,* ‘*Loss’* and ‘*Stigma’. ‘Loss’* is a topic that is shown in numerous studies that highlight similar aspects including a loss of identity that can occur following an initial experience of psychosis (Conneely et al., 2021).Similarly ‘*Stigma’* is a common experience that occurs for individuals who have lived with psychosis and has been frequently shown in research (Eliasson et al, 2021).

The main generative mechanisms theorised in this model, those of *‘Internal/ External Catalyst for Change’* and the *‘Psychosis Experience’* itself,are for the majority supported by current research. The ‘*Psychosis Experience’* and the content of the symptoms of psychosis are noted by previous research as being a facilitator for positive change as seen in the results this has been suggested to be predominantly due to the individuals meaning making and life experiences (Jordan et al, 2020). In a systematic literature review carried out by Ng et al (2021) across 37 papers, they identified that the main facilitators of the ‘*Positive Changes’* were, Personal identity and strength, Receiving support, Opportunities and possibilities, Strategies for coping, Perspective shift, Emotional experience, and Relationships (PROSPER). Similar themes can be seen in the sub-categories of ‘*Internal Catalysts’* and ‘*External Catalysts’*. Specifically, the confidence and strength participants identified in themselves, and the role of relationships and opportunities found in professional support. Peer support is noted as being a potentially key support that some of the participants accessed, it is suggested in other research as specifically helping foster hope and making positive identity changes (Shane et al, 2019). Finally, the role of an individual’s ability to engage in Self Reflection identified in this study as an internal catalyst is usually suggested as a positive change that occurs following on from the experience of psychosis (Jordan et al, 2018) although this could be seen as a vital part of the perspective shift and identity noted in PROSPER (Ng et al, 2021).

Interestingly, while several participants made note of the role that time took in their recovery and the development of positive changes, the role of time or temporal effects on outcomes in psychosis and the development of *‘Positive Changes’* are currently under researched (Ng et al, 2021). Despite numerous studies noting an influence of time this is not usually explored further, with studies instead focusing on the need for more research specifically into the effect of time on psychosis recovery and the development of positive changes (Heron et al, 2012; Law & Morrison, 2014). Theories of time impacting mental health and recovery are mixed. With, some theories suggesting that time can lead to affect fade by which the effect of difficult situations decreases with time (Crawford & Marsh, 2023) and others suggesting that time without support can lead to worse outcomes (Manrique et al, 2020). Similarly this could also be supported by the theory of spontaneous resolutions in psychosis whereby individuals naturally recover due to the variations in trajectories of the symptoms (Palaniyappan, 2019).

The *‘Positive Changes’* identified in the research namely *‘Resiliency’, ‘Self-Identity’, ‘Stronger Personal Relationships’, ‘Social Life’* and a ‘*Greater Appreciation for life’* are commonly found positive changes that occur following on from an experience of psychosis (Jordan et al, 2018; Slade et al, 2019; Ng et al 2021). While the positive change to ‘*Advocacy/Career’* could be seen as being similar to the positive change of recognition of new possibilities or directions in one’s life purpose (Slade et al, 2019). Furthermore, while not directly related to the experience of psychosis, changes in career or increases in advocacy is a common feature of the theory of PTG and positive changes following other mental health experiences (Prescod & Zeligman, 2018). This change could be seen as part of the sense making and growth seeking that individuals who experience challenging situations may engage in and could also be linked to the increase in ‘*Empathy’* that was highlighted as a main positive change, as individuals relate and empathise with others who may be going through similar struggles and wish to help or support them while also helping to counter or change the discrimination and stigmatising beliefs that individuals may have experienced (Vaughan & Hansen, 2004).

‘*Empathy’,* when discussed in relation to psychosis varies across studies with some studies focusing on the effect of psychosis on reducing empathy in individuals (Achim et al, 2010; Freidman et al, 2023). Other studies do show that following on from the experience empathy can increase (Kong et al, 2021). However, this seemed to depend on a number of factors including the type of intervention and the empathetic nature of an individual before their experience (Grumley et al, 2010; Duñó et al, 2020). Whereas the results of this research would suggest that regardless of treatment, personal or environmental factors empathetic tendencies increased following an experience of psychosis.

The ‘*Maintenance of Positive Changes’* is an important factor of the model as they help to explain a key feature, namely why the ‘*Positive Changes’* are long lasting for the individual. The maintenance factors such as the relationships individuals have, coping strategies they developed to help with psychosis symptoms as well as the ongoing professional support that they may be accessing are understandable as maintenance factors and are commonly found in research into positive changes following psychosis (Tweedell et al, 2004; Jordan et al, 2018). Less seen in previous research is the concept of *‘Positive Changes’* maintaining themselves and helping to maintain and develop other ‘*Positive Changes’* best conceptualised by Victoria who described the phenomena as an ‘an upward cycle of positive effects’ and increased engagement in ‘*Advocacy/Career’* changes and ‘*Empathy’* helped participants to see and experience other positive changes and finally the improvements in ‘*relationships’ and ‘Social Life’*could be seen as helping participants be accountable to and supported by others helping maintain the *‘Positive Changes’*.

While most of the broader categories of the emergent theory are supported by the current literature there are certain elements namely generative mechanisms of the *‘Positive Changes’*, ‘*Maintenance of Positive Changes’* and subcategories that could be seen as either novel or underrepresented in the current view of psychosis itself and the positive changes following the experience of psychosis. The most prominent underrepresented aspect is the inclusion of ‘*Pleasant/Comforting’* subcategory of the psychosis experience and how these may have been used as a coping strategy by participants.

### Clinical Implications and Recommendations

The emergent theory and explanatory model could help to inform clinical practice in services working with individuals experiencing psychosis. The emergent theory itself offers some explanation for how *‘Positive Changes’* could be facilitated by these services and how these positive changes could be maintained. The model could also be helpful in explaining some of the complexities around the experience of psychosis, namely the, at times underrepresented, principle that psychosis experiences can be a combination of *‘Pleasant/Comforting’, ‘Unpleasant/Scary’* and ‘*Neutral*’. This could aid with psycho-education and normalisation for a greater breadth of psychosis experiences.

From the participants’ varied experiences of mental health services, certain aspects of their experiences were noted as being more beneficial; the person centred and holistic nature of the care they received and the agency and power that they felt that they had during the time they were receiving professional care. Therefore, it is possible to recommend to service providers and health care professionals working with individual’s currently experiencing psychosis that they employ more of a holistic approach, meaning an approach that encompasses the entirety of their experiences both social and those related to their psychosis (Phan et al 2021), while also actively empowering and encouraging individuals they are working with to make informed decisions about their health care.

### Limitations

There are several limitations to the research mostly due to the method of recruitment. Recruitment via social media, in theory, offers greater opportunity for recruitment of lesser heard voices (King et al, 2014) and was considered as useful to access individuals with psychosis as there is often difficulty with recruitment (Bucci et al, 2015). However, it is worth noting that for participants who took part in this study five out of eight were involved in research or directly working in mental health fields and the remaining three are heavily involved in advocacy. This could have affected the ‘*Positive Changes’* that occurred and the level of reflexivity and insight demonstrated by participants. This could also highlight that despite the method of recruitment being aimed at recruiting lesser heard voices this may not have been the possible. Therefore, future research should aim to address this possibly through using online groups, or increasing the time available for recruitment. Furthermore, due to the self-report method of identifying psychosis it is difficult to guarantee that all the participants reached the thresholds for a psychosis diagnosis or participants may have had other co-morbid conditions that could have affected their experience and therefore the positive changes that occurred. This could be mitigated in the future by recruiting though NHS services such as EI teams. Although it is worth noting that while there are uncertainties and limitations to using social media the strengths of this method, such as preventing gate-keeping by staff, being able to reach lesser heard voices and gaining a more diverse sample with a greater breadth of experience may help to counter some of the limitations.

### Future Research

The diagram representing the emerging theory contains relatively broad terms within each of the categories. The categories *‘Maintenance of Positive Changes’* and ‘*Internal/ External Catalyst for Change’* could be explored in more depth to more accurately assess how positive changes occur within the population and how they can be maintained. One of the gaps identified in current research and briefly noted in this research is the impact that time has on the development and ‘*Maintenance of Positive Changes’*, further studies possibly utilising longitudinal methods could be beneficial in assessing the effect that time has on outcomes in psychosis.

## Conclusion

The research provides some novel and previously unexplored or underrepresented insights into the experience of psychosis and the positive changes that can occur. The results provide further evidence in support of the phenomena while also helping to consider and provide potential generative mechanisms by which positive changes are facilitated and maintained.

The majority of the categories found in this research are supported by the existing literature and understanding. While, it also provides under researched ideas and insights namely including the presence of ‘*Pleasant/Comforting’* psychosis experiences and the role that these can take in the facilitation of *‘Positive Changes’* as well as the idea that *‘Positive Changes*’ can maintain themselves. One of the most noticeable deviations from current research is the move from only focusing on the psychosis experience as defined by negative concepts such as suffering.

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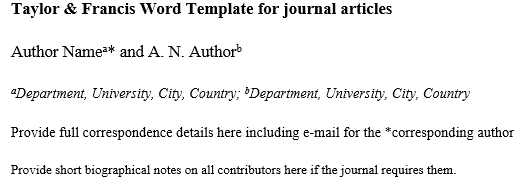
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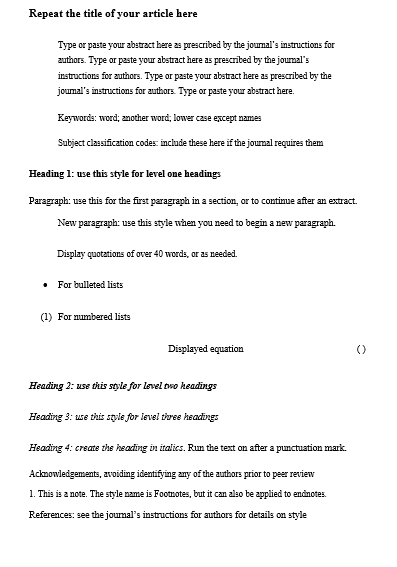
Woodall, A., Morgan, C., Sloan, C. (2010). Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers?. BMC Psychiatry 10, 103 <https://doi.org/10.1186/1471-244X-10-103>

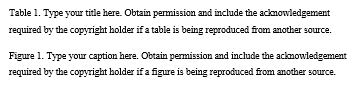
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## Appendix

### Appendix 1 – Formatting Guidance and Template for Authors







### Appendix 2 – Recruitment Poster



**Exploration into Perceptions and Understanding of Positive Changes Following the Experience of Psychosis**

This research is interested in discussing your experiences of positive changes following an experience of psychosis. Looking to explore your experiences, perception and understanding of these positive changes.

Light bulbs drawn on a blackboard

Description automatically generated with medium confidence

If you would be interested in taking part in an interview up to 60 minutes (online or by phone) to speak about your experiences please contact me directly for more information:

A person with long hair and glasses

Description automatically generated with medium confidenceCharlie Piper

Trainee Clinical Psychologist

Staffordshire University

[p024988k@student.staffs.ac.uk](mailto:p024988k@student.staffs.ac.uk)

***Thank you for reading this invite and for considering taking***

***part in this research***

### Appendix 3 – Information Sheet

**INFORMATION SHEET FOR PARTICIPANTS**

*Project Reference Number:* SU\_22\_079

**Title of study**

Exploration into Perceptions and Understanding of Positive Changes Following the Experience of Psychosis

**Invitation**

I would like to invite you to take part in this research project as part of my Doctorate research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

This study is to explore your beliefs and understanding of positive changes following an experience of psychosis to gain a better insight in to the phenomena. Long lasting positive change can occur after experiencing difficulties such as psychosis. However, it is possible that you may not see psychosis as having been a difficult experience but you still see positive changes having happened due to your experience of psychosis.

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

You have been invited to take part as you see yourself as someone who has experienced positive changes in your life following an episode of psychosis

**What will happen if I take part?**

You will be invited to take part in an interview at a time and date that works for you. The interview will ask a number of questions regarding your experience and understanding of positive changes following on from an experience of psychosis.

If you choose to take part, the interview can be conducted either using Microsoft Teams video call or phone call depending on which you would prefer. The interview should take no longer than one hour but can be shorter depending on your availability.

The interview will be recorded and then transcribed so that the information can be analysed by the researcher. The research may include direct quotes from your interview and include them in the write up of the research. The type of recording will depend on what you consent to this can be either audio or video depending on your preferences. You will be informed by the researcher before any recording begins.

If you choose, or would like to be contacted after the interview to discuss the analysis of your interview this can be arranged. This would involve discussing with the researcher the results of your interview to ensure that the analysis reflects your experiences and understanding.

**Do I have to take part?**

No, taking part is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact me if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign a consent form to confirm this.

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

The study will be asking questions about your experiences of psychosis. As this can be a sensitive topic it is possible that you may find the conversation uncomfortable or upsetting if this is the case you have the right to not answer a question, ask to move on, take a break or with draw from the interview.

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

There are no intended benefits of taking part in this research. Other than the opportunity to discuss your experiences and potentially improve understanding in current research.

**Data handling and confidentiality**

Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2016 (GDPR).

Your data will be stored on a secure Staffordshire University Server and any hard copies of consent forms or personal information will be scanned in to a computer and the hard copies destroyed. For the purposes of the thesis you will be assigned a random identifier and any personal identifiable data will be either omitted or changed to ensure anonymity. The data will only be shared with members of the research team. After the data has been collected and analysed it will be anonymised and stored by Staffordshire University for a period of 10 years.

**Data Protection Statement**

The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a ‘task in the public interest’ You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the GDPR. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the Staffordshire University Data Protection Officer. If you wish to lodge a complaint with the Information Commissioner’s Office, please visit [*www.ico.org.uk*](http://www.ico.org.uk/).

**What if I change my mind about taking part?**

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up to two weeks after your interview, if you choose to withdraw during this time your data will not be kept or stored. After two weeks withdrawal of your data will no longer be possible due to your data being analysed and processed at which point it will be completely anonymous and will not be able to be removed from the write up of the thesis.

If you choose to withdraw from the study, within two weeks, we will not retain any personal information that you have provided us as a part of this study.

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

The results of the study will be analysed and then written up for a Doctorate thesis with the aim to publish the research in a scientific journal.

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact me using the following contact details:

Charlie Piper

Email: [p024988k@student.staffs.ac.uk](mailto:p024988k@student.staffs.ac.uk)

Phone : 07971 79292971

**What if I have further questions, or if something goes wrong?**

 If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

**Research Supervisor:** Dr Gary Lee

[gary.lee@staffs.ac.uk](mailto:gary.lee@staffs.ac.uk)

**Staffordshire University Ethics Committee:** Dr Edward Tolhurst (Chair of Research Ethics within the School of Health and Social Care)

[ethics@staffs.ac.uk](mailto:ethics@staffs.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research. If you would like more information or feel you need support details can be found attached below**

**Where can I get Support?**

If you wanting support, please call the NHS 111 number, visit NHS Choices Website [www.nhs.uk](http://www.nhs.uk) or make an appointment with your GP. In a crisis please contact 999 immediately.

**Where Else Can I Get Support?**

Whether or not you decide to make an appointment to see your GP, there are lots of other services where people who experience psychosis can get support. These include:

Helplines

Samaritans: [www.samaritans.org](http://www.samaritans.org/) | 08457 90 90 90 | jo@samaritans.org  
A 24-hour confidential helpline that is open 365 days a year

Rethink Advice Line: 0300 5000 927  
Open Monday – Friday, 10.00am – 1.00pm, offers practical advice and information

Peer Support

Hearing Voices Groups: info@hearing-voices.org | [Find A Group](http://www.hearing-voices.org/hearing-voices-groups/find-a-group/)  
Use this website to find out if there are any Hearing Voices Groups in your area. If there aren’t any groups locally, you may want to speak with a local mental health charity to see if they are interested in starting one. All groups are run independently of the Hearing Voices Network – our aim is to help people create these spaces, support them and connect them with people who hear voices.

The hearing voices network also provide free leaflets and booklets for self help with distressing voices and coping strategies [www.hearing-voices.org/resources/free-downloads/](http://www.hearing-voices.org/resources/free-downloads/)

Voice Collective: 020 7911 0822 | [www.voicecollective.co.uk](http://www.voicecollective.co.uk/) | info@voicecollective.co.uk  
A UK wide London-based project that supports children and young people who hear voices, see visions, have other ‘unusual’ sensory experiences or beliefs. Email them for more information, or see their online support forum [www.forum.voicecollective.co.uk](http://www.forum.voicecollective.co.uk/).

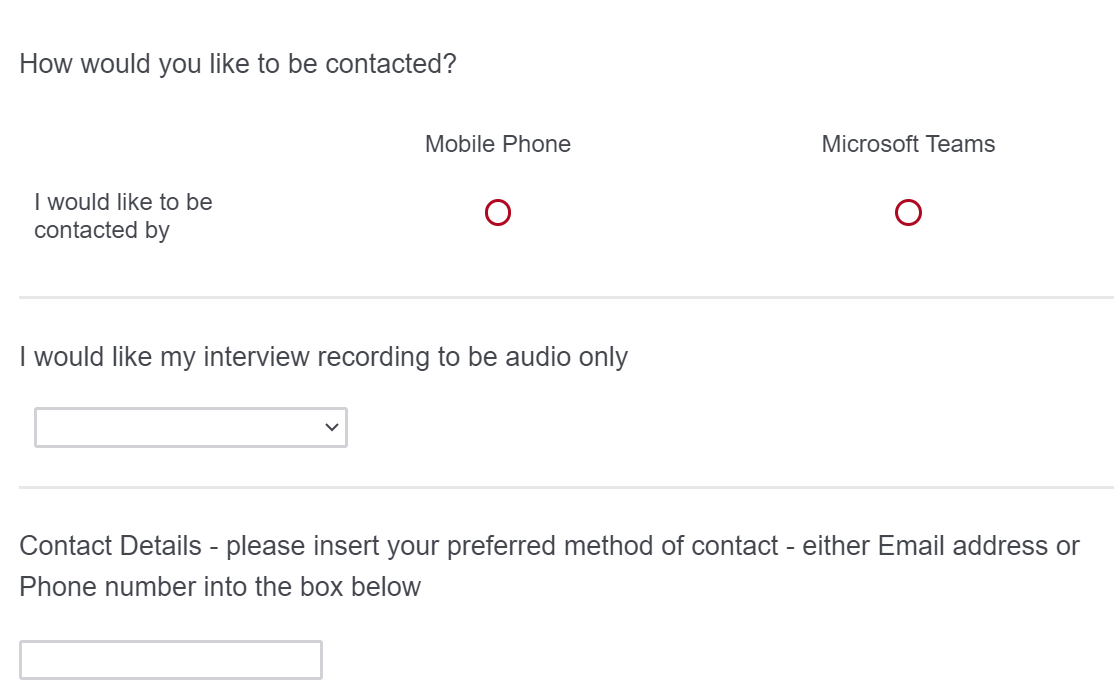
**Where can I find More Information?**

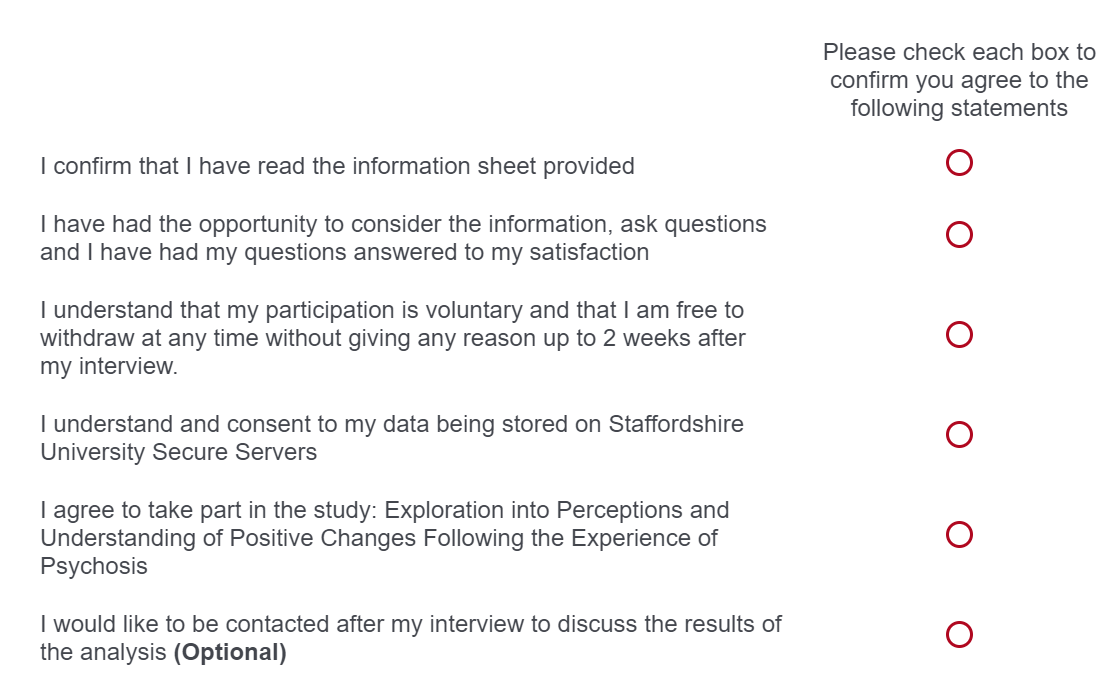
If you would like more information on psychosis, support or treatment this can be found in the following places:

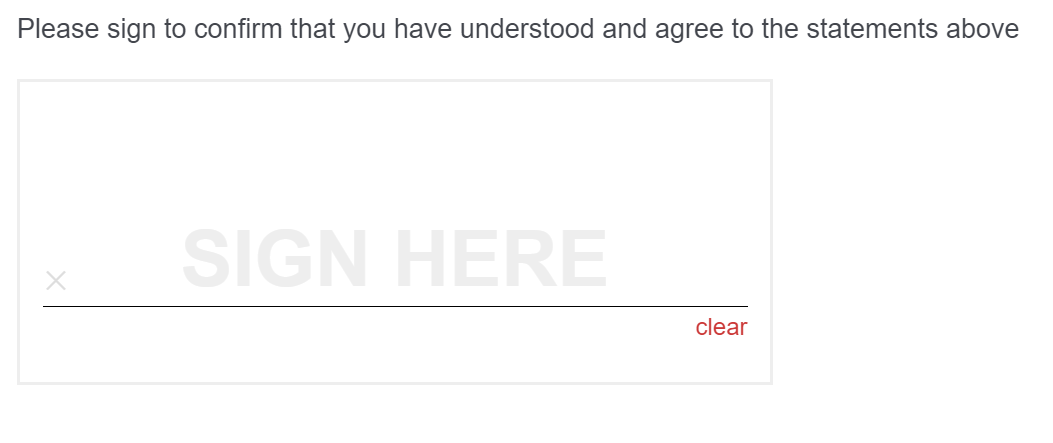
Mind (a mental health charity who provides advice and support to empower anyone experiencing a mental health problem) [www.mind.org.uk/information-support/types-of-mental-health-problems/psychosis/self-care/](http://www.mind.org.uk/information-support/types-of-mental-health-problems/psychosis/self-care/)

### Appendix 4 – Consent Form









### Appendix 5 – Debrief Form

**Research Debrief Form**

Title of Project: Exploration into Perceptions and Understanding of Positive Changes Following the experience of Psychosis

I would like to start by sincerely thanking you for taking part in this study. Your response has been really helpful in developing our understanding of positive changes that may have occurred due to an experience of psychosis.

The purpose of this form is to provide you with information on the aims of this study, what will happen to the data you have provided, your rights to withdraw, and to provide you with information on where you can find help and information should you feel you need it.

**Purpose of this study**

The aim of the study is to try and gain a better understanding of the lived experience of positive changes from the perspective of individuals, such as yourself, with an experience of psychosis.

This study is looking to explore your understanding and insight into these positive changes to gain a better insight into the phenomena and is looking for answers to the following questions.

1. How do individuals with an experience of psychosis understand positive changes that may have occurred due to their experience?
2. Why does this positive change occur?

**Confidentiality**

The information provided in your consent form will be stored on a secure Staffordshire University server. The recording of the interview from today will be transcribed and the recording will then be permanently deleted.

After the transcript has been created and analysed it will be anonymised. This is done by removing all identifiable data, such as names and locations. Direct quotes from your interview may be included in the research, however, these quotes will not include any identifiable information. The transcript with be stored by Staffordshire University for a period of 10 years.

**Withdrawal**

If you decide after your interview that you no-longer want to be included in the study you will have up to 2 weeks to contact either myself, Dr Gary Lee or the Staffordshire University Ethics Committee to remove your data from the study. Beyond 2 weeks it will no-longer be possible to remove your information from the research.

**Where can I get Support?**

If you wanting support, please call the NHS 111 number, visit NHS Choices Website [www.nhs.uk](http://www.nhs.uk) or make an appointment with your GP. In a crisis please contact 999 immediately.

**Where Else Can I Get Support?**

Whether or not you decide to make an appointment to see your GP, there are lots of other services where people who experience psychosis can get support. These include:

Helplines

Samaritans: [www.samaritans.org](http://www.samaritans.org/) | 08457 90 90 90 | jo@samaritans.org  
A 24-hour confidential helpline that is open 365 days a year

Rethink Advice Line: 0300 5000 927  
Open Monday – Friday, 10.00am – 1.00pm, offers practical advice and information

Peer Support

Hearing Voices Groups: info@hearing-voices.org | [Find A Group](http://www.hearing-voices.org/hearing-voices-groups/find-a-group/)  
Use this website to find out if there are any Hearing Voices Groups in your area. If there aren’t any groups locally, you may want to speak with a local mental health charity to see if they are interested in starting one. All groups are run independently of the Hearing Voices Network – our aim is to help people create these spaces, support them and connect them with people who hear voices.

The hearing voices network also provide free leaflets and booklets for self help with distressing voices and coping strategies [www.hearing-voices.org/resources/free-downloads/](http://www.hearing-voices.org/resources/free-downloads/)

Voice Collective: 020 7911 0822 | [www.voicecollective.co.uk](http://www.voicecollective.co.uk/) | [info@voicecollective.co.uk](mailto:info@voicecollective.co.uk)  
A UK wide London-based project that supports children and young people who hear voices, see visions, have other ‘unusual’ sensory experiences or beliefs. Email them for more information, or see their online support forum [www.forum.voicecollective.co.uk](http://www.forum.voicecollective.co.uk/).

**Where can I find More Information?**

If you would like more information on psychosis, support or treatment this can be found in the following places:

Mind (a mental health charity who provides advice and support to empower anyone experiencing a mental health problem) [www.mind.org.uk/information-support/types-of-mental-health-problems/psychosis/self-care/](http://www.mind.org.uk/information-support/types-of-mental-health-problems/psychosis/self-care/)

**What if I have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Research Supervisor: Dr Gary Lee

[gary.lee@staffs.ac.uk](mailto:gary.lee@staffs.ac.uk)

Staffordshire University Ethics Committee: Dr Edward Tolhurst (Chair of Research Ethics within the School of Health and Social Care)

[ethics@staffs.ac.uk](mailto:ethics@staffs.ac.uk)

Should you have any further questions regarding this research please do not hesitate to get in contact.

Best Wishes   
  
A person with long hair wearing glasses and a lanyard

Description automatically generated with medium confidenceCharlie Piper

Trainee Clinical Psychologist

Staffordshire University

[p024988k@student.staffs.ac.uk](mailto:p024988k@student.staffs.ac.uk)

### Appendix 6 – Example Questions

Proposed Interview Schedule for first participant

The below questions are intentionally broad and open ended with the intention to change as coding and analysis of first interview suggests areas for further exploration as is typical of Grounded Theory approaches

1. Can you tell me about your experiences of Psychosis?
   1. When did you first start to notice symptoms associated with psychosis?
   2. How long did these symptoms last?
   3. What was the nature of your psychosis experience? (e.g. audio/ visual hallucinations, behaviour changes, thought changes)
   4. Do you think your experience differs to other peoples? If so how?
2. What support if any did you receive during this time?
   1. Did you ever receive any formal treatment or support? (e.g. from early intervention services)
   2. Did you receive any informal support? (e.g. friends, family, social or community groups)
3. Can you tell me about your life now compared to your life before your experience of psychosis?
   1. What has changed in your life?
   2. What was your life like before your experience?
4. What positive changes have you identified in your life that you credit to your experience of psychosis?
5. Why do you think you these positive changes occurred for you?
6. Is there anything else about your experiences of psychosis or positive changes that you think are important?
7. Is there anything else that you think would be important to include

### Appendix 7.1 – Example Transcript (Miranda) Open Coding

### Appendix 7.2 – Example Transcript (Miranda) Selective & Theoretical Coding

### Appendix 8 – Example Memo from Participant 6

|  |  |
| --- | --- |
| **Memo – Incorporating Neutral Experiences of Psychosis** | |
| When asked about their initial experience of psychosis, (participant 6) noted that they ‘started off neutral’ before turning negative and once again becoming neutral. So far the when asked about their experiences participants have mostly focused on either ‘*Negative’ or ‘Positive’* experiences.  ‘*Negative’* – either scary or uncomfortable experiences, usually either visual, auditory or tactile hallucinations.  ‘*Positive’* – Experiences that provide a level of comfort or are in some way pleasant.  ‘*Neutral’ –* Neither Positive or Negative and is seen to have no significant Impact on the individual  I’m still uncertain about the sub-category names, as ‘*Positive’ and ‘Negative’* are also used as terms within the symptoms of psychosis | ‘*Psychosis Experience’*  Sub-Categories  ‘Positive’  *‘Negative’*  Emergent:  ‘*Neutral’* |
| **How do Psychosis Experiences Interact?**  From the interview with (Participant 6) can the experience of psychosis be described as existing on a spectrum *“It can be positive, it can be terrible, it can be neutral”.* Whereby individuals experience either/ or, positive, negative and neutral experiences | |
| **Where does this fit within the Psychosis Experience?**  Some suggestion from (The Participant) that their hallucinations began as neutral and then began to change, could this be an effect of ‘*Time’* or the ‘*Initial Perceptions of Psychosis’?*  (It could be worth looking into if there are other papers with list ‘*Neutral’* experiences) | |
| **How does this effect the theory?**  Possible change to the demonstration of the ‘*Psychosis Experience’*    from  Negative  Positive  To  Neutral  Negative  Positive | |

### Appendix 9 – Extract from Reflective Log

# Paper 3: Executive Summary

## Positive Changes Following an Experience of Psychosis: A Grounded Theory Exploration

A person with long hair wearing glasses and a lanyard

Description automatically generated with medium confidence

Charlie Piper

Trainee Clinical Psychologist

Staffordshire University

Word count – 2,383

## What is an executive summary and who is it for?

The purpose of an executive summary is to clearly communicate the results of a doctoral piece of research in a way that is easily understandable. They are typically written specifically for the participants of the research who have given their time to take part. However, participants themselves voiced the hope that this research would be able to help other people who are experiencing psychosis and give them hope for positive change. They also wanted this research to aid services in working with individuals experiencing psychosis.

Therefore, this executive summary is aiming to be accessible to both those who are currently experiencing psychosis as well as the health care professionals who work with them. To aid with ensuring usefulness and accessibility of the research, this paper has been reviewed by professionals from an Early Intervention team and participants of the study who opted to be contacted following their interview. They were asked to provide feedback and potential adjustments, also helping to ensure the results fit with their experiences.

## Project Summary

The aim of the project was to better understand the lived experience of psychosis and answer the following two questions:

1. How do individuals with an experience of psychosis understand positive changes that may have occurred due to their experience?
2. What causes these positive changes?

In the process of answering these questions a theory of how people experience and understand their psychosis and positive changes was developed which gives an insight into what positive changes occur, the cause of positive changes and what maintains these positive changes.

## Background Information

The word Psychosis is often used to describe a collection of symptoms that have an effect on the mind where beliefs, thoughts, feelings, senses and behaviours may be altered. It is believed that roughly 0.7% of individuals aged 16 and over will have an experience of psychosis.

Positive changes is a term that refers to long lasting improvements that people have identified in their lives. Within the context of this project these positive changes are seen as having happened because of the participants’ experience of psychosis. When specifically linking this to the experience of psychosis previous research has found that following an experience of psychosis, individuals have said that that they have an increased appreciation for life in general, more meaningful relationships, increased feelings of personal strength and richer existential and spiritual lives.

## Study Information

This project makes use of ‘qualitative’ methods, which means that the participants were interviewed, and these interviews were recorded and then analysed to assess the information gained. The project, specifically, uses a method called Grounded Theory.

Grounded theory is a method by which the researcher collects and analyses information from participants with the aim of generating a theory or explanation of their experiences.

## Steps in data collection

The following eight steps were followed in the recruitment, interview, and analysis process:

1. Participants were recruited though the use of social media (e.g. Facebook, Twitter and Reddit)
2. Eight individuals who identified as having positive changes that they linked to their experience of psychosis were recruited and sent information and consent forms.
3. Participants took part in unstructured interviews, via Microsoft Teams that lasted between 45 – 60 Minutes. After the interview debrief forms were sent.
4. These interviews were recorded and then transcribed
5. After each interview the transcript was analysed and initial themes were identified which helped to create new areas for exploration in the following interview
6. The next interview was then completed and steps 4 and 5 were repeated.
7. Categories are used to create an ‘emergent theory’ to explain experience of participants
8. Recruitment, interview and analysis continues until ‘data saturation’ (point at which no new information is gained from interviews)

## The Theory

Maintenance of Positive Changes

Internal/ External Catalyst for Change

## Explanation of the Theory

The diagram above is the theory that has been created to explain the experiences of positive changes and psychosis described by the participants of this project. The theory is created from five core categories:

1. Psychosis Experience
2. Initial Perceptions of Psychosis Experience
3. Internal and External Catalyst for Change
4. Positive Changes
5. Maintenance of Positive Changes

These categories and how they are linked are described in more detail below and an example from a participant is given.

*Psychosis Experience*

Specific psychosis experiences can vary dramatically, e.g. the content of individuals hallucinations or delusions. However, broadly these experiences could be split in to three distinct sub-categories:

* ‘Difficult/Unpleasant’
  + Those experiences that participants found distressing
  + e.g., hallucinations that were seen as scary, “bugs crawling under my skin”(Miranda)
  + These experiences were often linked to emotional distress such as high levels of anxiety or feelings of embarrassment.
* ‘Pleasant/ Comforting’
  + Those experiences that provided a sense of comfort or were supportive for participants.
  + E.g., “she’s a… 2 and 1/2 feet high, fluffy grey cat, with very pale eyes… she blinks very slowly at me, and it's always been very comforting” (Miranda)
* ‘Neutral’
  + Neither Unpleasant or Pleasant experiences.
  + E.g., “I see my hallucinations almost, like, neutral…. like if you've just got a problematic old relative who says crap but know they’re a bit odd… you love them anyway” (Victoria)

What is important to note is that the experience was not necessarily as simple as once or the other e.g. Pleasant, Unpleasant or Neutral, and could be a combination such as “Magical in a way but… also quite scary” (Sarah) and were neither “entirely negative… or an entirely positive thing” (Luke). It is for this reason that the Psychosis Experience is shown as circular where someone maybe experiencing any of the sub-categories at any one time.

*Initial Perceptions of Psychosis Experience*

The initial perceptions of psychosis were the general beliefs and understandings that participants had of their immediate experiences following on from when they first noticed that they were experiencing psychosis. While again where was a lot of variation these could be seen to be included in the sub-categories ‘*Loss’* and ‘*Stigma’*

*‘*Loss’

* Participants felt that they lost:
  + Identity/ sense of self
  + Relationships
  + Social Lives
  + Work
  + Confidence
* “I went through grieving, for all my losses” (Sarah)

‘Stigma’

* Participants experiences of the negative and unfair beliefs that are held about psychosis, this was both beliefs held by society (external stigma) and beliefs held by participants themselves (Self-Stigma)
  + External stigma e.g. people being told “you can't stay the night because I'm afraid you're going to kill me in your sleep” (Sapphire),
  + Self-Stigma e.g. “I never told his family because I didn't think that they would get it I thought that they would treat me differently” (Miranda)

*Internal/ External Catalyst for change*

Most participants identified that there were specific facilitators for positive changes and this category demonstrates the participants perceptions of what caused the positive changes to occur for them. These are split into the personal experiences, values and skills (Internal) and the support that they may have received (External).

‘Internal Catalysts’

* This included the participants previously gained values and skills, including their ability to reflect on the experience of psychosis and power that they felt that they had to advocate for themselves.

‘External Catalysts’

* These were the support systems that the participants experienced mainly focusing on the professional support, such as Early Intervention Teams and Therapists, and social support, such as friends and family.

*Positive Changes*

There were seven main positive changes that participants identified as having occurred in their lives as a direct result of experiencing psychosis. These were improvements with ‘*Empathy’, ‘Resiliency’, ‘Self-Identity’, ‘Advocacy/ Career’, ‘Stronger Relationships’, ‘Social Life’* and a ‘*Greater Appreciation for life’.*

*Maintenance of Positive Changes*

The final category attempts to understand what maintains these positive changes. Participants described the following as helping to maintain these positive changes:

* Internal/ external catalysts for change, such as close family, friends, partners and children made people “accountable to more people than just myself” (Luke).
* Developing routines and coping strategies that worked for them
* The positive changes help to maintain themselves in “an upward cycle of positive effects” (Victoria).

## How it all fits together

The arrows on the diagram demonstrate the links between the categories with ‘Psychosis Experience’ at the top which then moves to the ‘Initial Perceptions of the Experience’ which were the immediate experiences of the participants. At some point the participants experienced an ‘Internal/ External Catalyst for change’ which alongside the experience of psychosis itself cause positive changes to occur. The positive changes were then maintained by a number of factors including catalysts for change and positive changes themselves. Finally, ‘Time’ played a key role in helping to build and maintain positive changes which is shown alongside the diagram.

## Discussion

Within Grounded Theory, the theory that is developed is then compared with ideas and research that already exists within the topic being researched.

Psychosis and its negative consequences have been researched and discussed frequently within existing research and most research into psychosis focuses on the experience as one of suffering. In this respect the sub-category ‘Difficult/Unpleasant’ experience of psychosis is supported by the current literature as is the ‘Initial Perceptions’ of ‘loss’ and ‘Stigma’ which are also commonly associated with the experience of psychosis. Less discussed are the experiences that are ‘Comforting/ Pleasant’ or ‘Neutral’ and the idea that they may co-occur is relatively novel.

The facilitators of Positive changes, in this project referred to as ‘Internal/ External Catalyst for Change’, are also similar to those found in previous research including the idea that the experience of psychosis itself may aid with the development of positive changes or at least help to predict it. Although the effect of ‘time’ is less researched and there are fewer examples that demonstrate how ‘time’ may affect the experience of psychosis.

Almost all of the positive changes that participants discussed have been seen in previous research articles which implies that the research is seeing similar patterns in the experience of psychosis. However, while there has been research into the effect of psychosis experiences on empathy research can vary with some studies claiming that individuals who experiencing psychosis may have decreased empathy

## Limitations and Future Research

No research is perfect and several limitations to this project exist. The method of recruitment for example, as while the use of social media allows for a greater number of individual to be reached those who took part in the study were vocal about their experience of psychosis and may not be representative of other people’s experiences.

The Categories ‘*Maintenance of Positive Changes’* and ‘*Internal/ External Catalyst for Change’* could be explored in more depth to improve understanding of how *‘Positive Changes’* occur and are maintained within the population. This may be researched through longitudinal studies to help assess the factors that support long term maintenance of positive changes.

## Recommendations and Clinical Implications

* Improve awareness of the complexities of the psychosis experience which could help to reduce stigma and allow for greater reflections.
* Encourage use of peer support groups
* Improved awareness and understanding of positive changes among clinical staff which can then be communicated to service users
* It is hoped that the research will be published in an academic journal
* Research will be presented to UK based Early Intervention Teams

## Conclusion

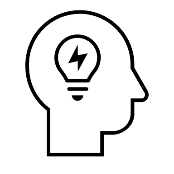
The findings of the research are supported by existing literature while also providing and developing new understanding and insight into psychosis and positive changes following the experience. The most significant ideas presented in this research are that the ‘*Positive Changes’* not only can maintain themselves but also help to create new *‘Positive Changes’* and that the *‘Psychosis Experience’* itself can generate *‘Positive Changes’*

This project also gives further evidence demonstrating that psychosis is a complex experience and individual’s experiences of it can vary dramatically and is not necessarily defined purely as a negative or positive. However, despite this variation positive changes occurred regardless.

## Messages from the Participants

Finally, each participant was asked what they would say to someone who is currently experiencing psychosis and what they wish someone had said to them, below are their responses.

It's okay to look after yourself and it's really important to do that, and gosh, if you trust me and give it a go, you'll really feel the benefits of it, also it's OK to be open with others, It's okay to show people your true self. You don't have to put on any airs and graces to impress people. You'll impress people a hell of a lot more by letting them see who you really are rather than trying to be who they want you to be.

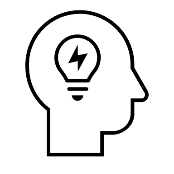


**Oliver**



You can make it but you got to start with you… and It's on you. You might not like it, but if you're gonna make it, you have to go within, not look outwards… that's when my whole life changed when I looked in.

**Sarah**



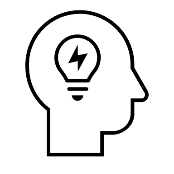
It's not the end of life… there are still things you can accomplish.

**Sapphire**



Psychosis can be truly fucking terrible at times, but it doesn't need to be... there's hope.

**Miranda**



you will and you can feel better and everything will be OK and you’re not alone and with time you can absolutely 100% come through it.

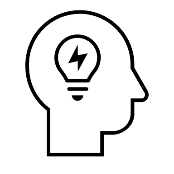
**Helen**

Things don't have to stay as they are forever. Things can get better. It is possible…. you do have autonomy. You do have agency. You can still make decisions for yourself and your limits can only be determined by yourself. It doesn't matter what a doctor tells you, it doesn't matter what a family member tells you that you can and can't do. You're the only one who can find that limit.



**Victoria**

Firstly, I'm sorry that you're going through this cause it's really tough and there are going to be days when you don't think that you can do it but don't, it's worse than hell but If you have the right people around you and you want to get better and you want to have a good life you deserve that, and you shouldn't let it wreck your life.



**Fiona**



Just keep going, it does get better and it always gets better. You’ve got to believe that even in the darkest times.

**Luke**