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## **PROFESSIONAL DOCTORATES**

### **Serious mental illness and wellbeing: An exploration of the impact of the Covid-19 pandemic and interventions to improve social functioning**

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*Serious mental illness and wellbeing: An exploration of the impact of the  
Covid-19 pandemic and interventions to improve social functioning*

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PRIFYSGOL  
**BANGOR**  
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Submitted in partial fulfilment for the degree of  
Doctorate in Clinical Psychology

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## Declaration

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

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Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

Signed:



'Date: 7/7/2021

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This was tough, thank you to everybody who made it bearable. Sarah for your love and laughter, listening to me in the darkest moments, and taking that slack whilst I was distracted. Esther and Sebastian for your light, love, and fun, the ultimate distraction. Mum and Dad for your faith in me and, just as importantly, your help with proofing, diagrams, and Excel spreadsheets. Mike and Robin for your warm words and wisdom that enabled me to find my way when I was lost.

I would also like to thank everyone who participated in my research for providing your deeply personal experiences in the name of science and progress. This project would not have been possible without you

## Thesis Summary

This thesis explores wellbeing and social recovery in people with serious mental illness.

Chapter one is a literature review drawing on Bourdieu's theory of capital to conceptualise mental health services as institutions with high levels of social capital. It then asks the question 'Can mental health services leverage this capital to improve social function in service users?'. Four types of intervention in which mental health services recruit members of the wider community to support social recovery are identified; peer support, befriending, shared activities, and social recovery therapy and rehabilitation. Thirteen controlled studies were identified, with three demonstrating a statistically significant effect for befriending and social recovery therapy on social function. Peer support or shared activity interventions were largely ineffective on these measures. The results are discussed in relation to social capital and whether its transfer, from mental health team to service user, may be impeded by stigma.

Chapter two is an investigation into the relationship between unusual experiences, wellbeing, and environment, for people with psychosis. Five people, using an early intervention service for psychosis, told their stories of their experiences of the Covid-19 pandemic. These stories were analysed, using a narrative methodology, to elucidate how wellbeing related attributions and unusual experiences developed over time in response to changes in the social environment. A complex account emerged of the interplay of different aspects of wellbeing over time. Integral to this interplay was the theme of '*struggle*' whereby participants worked tirelessly to maintain and enhance their wellbeing. Of particular interest was the struggle between connection to others and a coherent sense of self.

Chapter three is a discussion of the implications of these findings to clinical practice and research. Particular attention is paid to the difficulty in measuring 'recovery' in psychosis as it is an inherently idiosyncratic process.

# **Chapter 1 - Literature Review**



***What impact do interventions which engage the wider community have on social recovery in serious mental illness, a systematic review***

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This paper will be submitted to the International Journal of Mental Health Systems  
<https://ijmhs.biomedcentral.com/submission-guidelines/preparing-your-manuscript/review>

## **Abstract**

**Background:** Traditional psychological treatments for serious mental illness (SMI) struggle to demonstrate social functional recovery. People with SMI can be socially excluded, and typically have small social networks, which will hinder social functioning. Mental health services, on the other hand, are well connected to the wider community. Community engagement interventions seek to leverage the social capital of service providers to help people with SMI increase the breadth of their social networks.

**Methods:** A systematic search of the literature was carried out. Controlled evaluations of interventions that directly engaged members of the wider community to support people with enduring mental health problems to develop and expand their social networks were identified. Control groups were either active, waitlist, or treatment as usual. Outcomes were either subjective or objective measures of functioning.

**Results:** Four categories of interventions emerged: peer support, befriending, shared activity, and social recovery therapy and rehabilitation. There is preliminary evidence that befriending and social recovery therapy, but not peer support or shared activity, help increase social functioning in people with SMI. Objective measures of function appear to be more sensitive to change than subjective measures.

**Conclusion:** Befriending and social recovery therapy use resources accessible to most developed health care systems and can be of use to people with high levels of functional impairment. More research is needed to elucidate the relationship between social capital, mental health care interventions, and social functional recovery.

**Keywords:** Social Capital, Social Recovery, Social Participation , Serious Mental Illness, Peer Support, Befriending , Systematic Review, Social Networks, Social Function

## 1 Background

Social recovery, where people with severe mental illness (SMI) perform valued social roles and are engaged within their communities, is an important outcome for both mental health services (National Institute for Health and Care Excellence (NICE), 2014) and service users (Law & Morrison, 2014; Lloyd et al., 2017). However, psychological therapies struggle to demonstrate efficacy in this area. For example, in the United Kingdom (UK), two psychological interventions are recommended for people with psychosis; cognitive behavioural therapy (CBTp) and family therapy (NICE, 2014). However neither, in Cochrane reviews of effectiveness, demonstrate sustained recovery of social function (Jones et al., 2018; Pharoah et al., 2010).

Social recovery is operationalised in a variety of ways, with the construct of ‘social functioning’ most frequently used. A number of instruments purport to assess social function and such instruments generally measure the service user’s capacity to attain social roles and social performance (Burns & Patrick, 2007). Despite the existence of these measures, it is important to note that the social functioning has no universally accepted conceptualisation, and there are doubts that it can be measured validly and reliably given that it is highly sensitive to personal, social, and cultural preferences (Whitaker, 2013). For example, measures of social functioning can ask about frequency of activities such as bathing, starting conversations, or engaging in ‘pro-social’ activities such as going to a pub, museum, or cinema, all of which require an interpretation of what constitutes adequate functioning which will differ from person to person. Given these idiosyncrasies inherent to social functioning a second construct, a client’s satisfaction with their social situation, as measured by instruments of quality of life (QOL), is also considered an important indicator of social recovery (Priebe, 2007). As they are both psychological constructs, outputs from instruments measuring social function and QOL are difficult to interpret from a clinical perspective, for example an average change of 1.5 standard deviations on such a scale may be statistically significant but, on its own, the clinical relevance of such a change is not clear. To avoid these difficulties in interpretation, and to make the results of clinical trials accessible to a wider range of stakeholders, some (Barton, 1999; Bellack et al., 2007; Priebe, 2007) have argued for the use of objective measures of function which use ‘hard’ outcomes that can appeal to all stakeholder groups to evaluate the impact of the intervention on the lives of those taking part. Examples of such ‘hard’ outcomes include

social network size (see Anderson 2015 for review), employment and structured activity (Priebe et al., 2008; Hodgekins et al., 2015), living with partner or family (Priebe et al., 2008), and frequency of contact with others (Priebe et al., 2008).

Whichever way it is operationalised, as social competence, and individual's satisfaction with their social situation, or tangible changes to their social environment, social recovery depends, to some degree, on the access that individuals have to broad social networks that are well embedded within their community. It could be considered that therapeutic interventions, with their focus on psychological skills and emotion management, neglect the fact that people with SMI are often socially excluded with small, enclosed, social networks (Palumbo et al., 2015). Therefore, even if the therapy is successful, the clients lack of community engagement would continue to be a barrier to social recovery despite increases psychological proficiency.

Broad, well embedded, social networks are a form of social capital (Bourdieu, 1986) which provides opportunities for the acquisition of other forms of capital such as wealth, skills, qualifications, and culturally valued roles. For example, in order to find employment, or join a club or social group, someone has to be aware of existing opportunities, have access to suitable recommendations, and either possess the skills and knowledge required to fulfil the role or know someone willing to guide them. These opportunities will present themselves more frequently to people with larger, broader, and more embedded social networks. Defined in this way social capital could have a significant amplifying effect on an individual's functional abilities. Measures of social recovery in intervention studies for people with SMI may therefore be sensitive to the client's access to social capital.

In the UK mental health services are provided by a national, centrally funded, and centrally organised health service. In comparison to the marginalisation experienced by many mental health service users, health services form an important part of the communities they serve and therefore carry significant social capital. For example, 19% of all government spending in the UK is on health (The Health Foundation, 2018), a large proportion of the workforce are professionally trained and earn salaries in line with the UK average (NHS Digital, 2021), and with most people relying on health services at some point in their lives, the health service and its constituent workforce can be considered highly valued within the wider community. In a systematic review of interventions that support social participation for people with SMI Webber and Fendt-Newlin (2017) suggest that a mental health service can act as a link between

the service user and social networks in the wider community, essentially leveraging their social capital for the benefit of the user. Examples of this are befriending (Siette et al., 2017) and peer mentoring (White et al., 2020); interventions whereby members of the wider community are recruited to build relationships to support the service user in the ultimate goal of social recovery. As yet, there have been no systematic investigations into the full breadth of interventions that seek to recruit members of the wider community to support service users with social recovery, nor a systematic analysis of their impact on social functioning.

This systematic review will explore the impact of interventions that recruit members of the wider community to support people with SMI to achieve social recovery. The aim is to estimate the effect of such interventions and will focus on studies with control groups. Leveraging the social capital of mental health teams for the benefit of the service user is a relatively newly defined active ingredient in mental health interventions. Given the novelty of the approach it is likely that a significant proportion of evaluations are feasibility and pilot studies and are less likely to involve randomisation. Therefore, all controlled studies, regardless of randomisation, will be included to enable a broad synthesis of the available data. This review will also collate information on the core components of the interventions to allow for a better understanding of putative processes of change.

## **2. Methods**

### **2.1 Inclusion criteria**

#### **Intervention**

We aimed to include any intervention which a) recruited community members, or community groups, external to a participant's existing social network and b) aimed to facilitate social recovery. Recruitment could take the form of direct recruitment such as recruiting mentors, indirect forms such as partnering with existing community groups, setting up activities open to the wider community, or outreach work to engage external community resources. Social recovery was defined as increasing levels of activity within, or increasing connections to, the wider community in which the participant was situated. Therefore, interventions that could be described as self-help groups that focused on mutual support or skills development were not included, as they were not externally orientated. Likewise, interventions that recruited members of a service user's existing social network, such as open dialogue, were also excluded. Other criteria for exclusion were any intervention that focused on people with mental health problems in the criminal justice system, who were considered to have unique barriers to social inclusion, and any evaluation of a service design, such as a peer support agency.

#### **Study**

We included any study with at least two (pre and post) measures of effect for the intervention and the control group, regardless of randomisation.

#### **Control**

Comparison interventions could include medication, psychological therapies, treatment as usual (TAU) or non-specific/null or waitlist comparisons.

#### **Participants**

We included interventions for people with severe or enduring mental health problems, which are psychoses or severe affective disorders. This could be evidenced through clinician derived diagnosis, structured clinical interview, or those using mental health services set up for severe or enduring mental health problems.

## **Outcome**

Both subjective and objective measures of social recovery were included. Subjective measures of function were any self-rated, or observer-rated, validated, measures of social functioning or quality-of-life. To maximise the potential number of studies that could be included in the review, measures of personal mental health recovery were also included as it was considered that they too would pick up on participants' satisfaction with their social environment and capacity to perform social roles. Objective measures were any measure of the size of a social network, any measure of the quantity of social interactions, any measure of structured use of time.

## **2.2 Search strategy**

A systematic, electronic, search was conducted of databases, PSYCHINFO, MEDLINE, CINAHL, and Cochrane Central Register of Clinical Trials. Terms aimed at identifying interventions to promote inclusion, engagement, participation in social networks, communities, and neighbourhoods were combined, using Boolean operators 'and/or', with terms specifying serious mental illness and terms sensitive to controlled evaluations (see appendix 1). To maximise the sensitivity of the search the reference lists of key studies and identified reviews were searched to find studies which also fit the inclusion criteria.

The search was carried out by the first author DM on the 15/3/21 and studies identified were de-duplicated using Microsoft Excel. DM reviewed the titles and abstracts of the remaining studies for potential relevance, a 10% sub-set of the initial search was assessed by a second reviewer MJ. Full texts of potentially relevant studies were reviewed against the inclusion criteria, and 20% of these again reviewed by the second reviewer. Any disagreements regarding inclusion settled by discussion.

## **2.3 Data Analysis**

Data was extracted onto predesigned forms and included, citation, country, setting, study design, a brief description of the strategy, intervention, comparison intervention, and information about participants. The outcomes of interest were extracted; pre and post measures for both treatment and control, measures of variability, any reported measure of effect, and statistical analysis of the group x time interaction. Sub-group analyses, where pre planned and

relevant to the review's research question, were also extracted. Where information on the outcomes of interest was not reported authors were contacted; however if there was no response the study was still included, and the available data reported. Any information provided on how the intervention was proposed to work, the core components, was also extracted.

#### **2.4 Risk of bias (quality) assessment**

The Downs and Black (1998) quality checklist for health care interventions which provides a quality score, including risk of bias, for both randomised and non-randomised interventions, was used. Whilst more up to date checklists are available (L.-L. Ma et al., 2020) this checklist was used due to its relative simplicity and ease of use given the limited resources available. The Downs and Black (1998) quality checklist covers reporting, external validity, internal validity, and power. The checklist was adapted slightly for the purpose of this study. Firstly, an extra item was added to assess whether the study reported on how SMI diagnoses were established. Secondly, the power calculation item was altered to a binary outcome; 1 representing the presence of a power calculation and adequate power achieved, 0 representing no calculation, or power calculation present but adequate power not achieved. Finally, the item on distribution of confounders was adapted to a binary choice; 1 representing adequate reporting on the distribution of confounders and 0, inadequate reporting. The final revised checklist had 28 items with a maximum score of 28. It was recognised that using an adapted and out of date checklist would reduce the accuracy of identifying particularly low, or high, quality studies. However, this reduction in accuracy was considered acceptable given that the checklist was to be used to compare the relative strengths and weaknesses of included studies rather than as a method of exclusion or by way of quality comparison to other areas of research.

#### **2.5 Strategy for Data Synthesis**

Given the expected heterogeneity of interventions and outcomes a narrative synthesis was planned. Data on each outcome of interest were reported on separate tables, with some studies appearing on more than one table where multiple outcome measures were used. Only the outcomes for the sample as a whole were included in the tables with any subgroup analysis reported in the main text.



## **2.6 Preregistration**

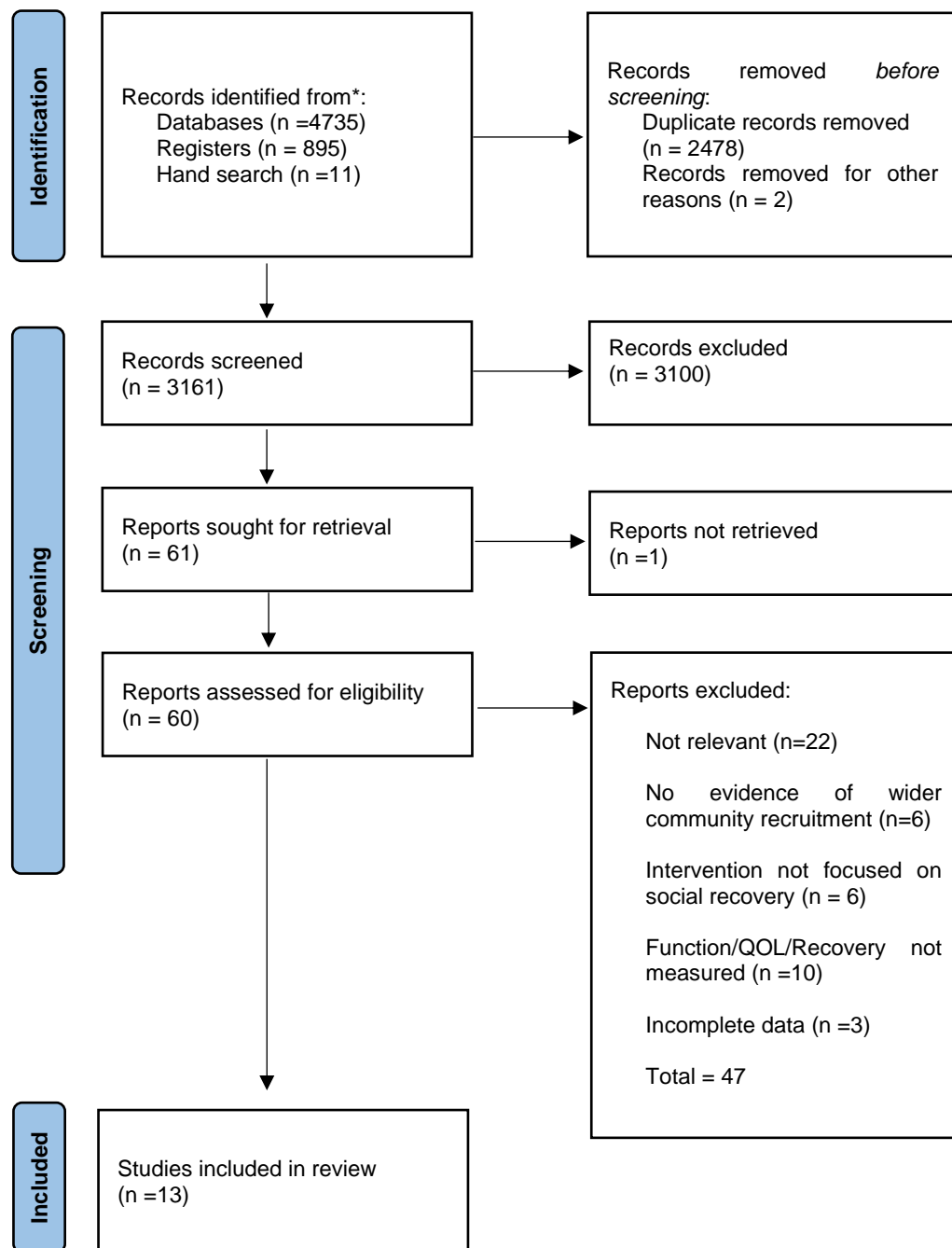
This review was preregistered with National Institute for Health Research (NIHR), Prospero registration number CRD42021241300

### **3. Results**

#### **3.1 Study Selection**

Figure 1 shows the flow diagram of study selection. The search strategy returned a total of 3,161 non-duplicate titles and abstracts. Sixty-one were considered potentially relevant, and full texts were assessed against the inclusion criteria. Thirteen papers were identified as eligible for inclusion. There was agreement between reviewers on 98% of titles and abstracts screened, and 92% of full texts reviewed.

Figure 1. Prisma Flow Chart of Systematic Review Search



### **3.2 Summary of the interventions included**

The thirteen studies included in the review fell into four categories of intervention; peer support, volunteer befriending, shared activities, and structured recovery or rehabilitation interventions (see table 1). One study (Davidson et al., 2004) was a three armed randomised control trial (RCT) with both a peer support arm and a befriending arm and is therefore reported twice under each heading.

Study Country		Sample size	Function Rel. Entry Criteria	Control Group	Provider	Context	BME (%)	Emphy'd (%) <sup>1</sup>	Objective Outcome	Subjective Outcome
PEER SUPPORT										
1	Chinman et al. (2013)  USA	N = 238 (Int. = 122) (Cont. = 116)	At least 30 inpatient days or 3 admissions in the last year	TAU	Peers embedded in MHT	Urban intensive support team	45%	NR	None	<b>QoL</b> ( <i>Quality of Life Brief Instrument</i> ) <b>Recovery</b> ( <i>MHRM</i> )
2	Craig et al. (2004)  UK	N = 45 (Int. = 24) (Cont. = 21)	A history of poor engagement	TAU	Peer embedded in MHT	Urban mental intensive support team	58%	NR	<b>Social network size</b> (Network interview)	<b>Relationship satisfaction</b> ( <i>Network interview</i> ) <b>Social Functioning</b> ( <i>Life skills profile</i> )
3	Davidson et al. (2004)  USA	N = 165 (Int. = 95) (Cont. = 70)	None	TAU	Volunteer agency recruiting clients from MHT	Rural and urban mental health teams	18%	20%	None	<b>Social Function (P)</b> ( <i>SOFAS</i> )
4	Felton et al. (1995)  USA	N = 104 (Int. = 36) (Cont. = 68)	Persistent and severe mental health problems	TAU	Peer embedded in MHT	Urban intensive support team	43%	14%	None	<b>QoL</b> ( <i>LQoL, social relations sub scale</i> )
5	Klein et al. (1998)  USA	N = 30 (Int. = 10) (Cont. = 20)	At least 2 admissions in the last 2 years and dually diagnosed	TAU	Peer support agency recruiting from a mental health team	Recruiting from a single urban intensive support team	73%	0%	None	<b>QoL</b> ( <i>LQoL checklist, friendship sub scale</i> )
6	Mahlke et al. (2017)  Germany	N = 216 (Int. = 114) (Cont. = 102)	None	TAU	Peer support team associated with MHT	Urban mental health team	NR	33%	None	<b>QoL</b> ( <i>MSLQ</i> )
7	Rivera et al. (2007)  USA	N = 136 (Int. = 70) (Cont. = 66)	At least 2 admission is the last 2 years	TAU	Peer embedded in MHT	Urban intensive support team	70%	NR	<b>Social Network Size / Frequency of social contact</b> ( <i>both network interview</i> )	<b>QoL</b> ( <i>LQoL, social relations sub scale</i> )

	<b>Study Country</b>	<b>Sample size</b>	<b>Function Rel. Entry Criteria</b>	<b>Control Group</b>	<b>Provider</b>	<b>Context</b>	<b>BME (%)</b>	<b>Emphy'd (%)<sup>1</sup></b>	<b>Objective Outcome</b>	<b>Subjective Outcome</b>
<b>BEFRIENDING</b>										
<b>8</b>	Davidson et al. (2004)  <i>USA</i>	N = 165 (Int.= 95 Cont.= 70)	None	TAU	Volunteer agency recruiting SUs from MHT	Rural and urban mental health teams	18%	20%	None	<b>Social Function (P)</b> <i>(SOFAS)</i>
<b>9</b>	Priebe et al (2020)  <i>UK</i>	N = 124 (Int. = 63 Cont. = 61)	Less than 60 mins a day on social or recreational activity	TAU	Volunteer co-ordinator. Sus recruited from local MHTs	Urban mental health teams	85%	6%	<b>Structured activity (P)</b> (TUS), <b>No. of Social Contacts (SCA),</b> <b>Objective Social Outcomes Index</b>	<b>QoL</b> <i>(MANSA)</i>
<b>10</b>	Sheriden et al (2015)  <i>Ireland</i>	N = 70 (Int. = 32 Cont. = 38)	Impaired social and vocational functioning, assessed by referring clinician	TAU	Volunteer co-ordinator. Recruited service users from MHT	Urban mental health teams	NR	NR	None	<b>Social Functioning</b> <i>(SFS)</i>
<b>SHARED ACTIVITY</b>										
<b>11</b>	Stein et al (1995)  <i>USA</i>	N = 28 (Int. = 14 Cont. = 14)	None	TAU	University department, recruited SU from local mental health team	Urban	NR	35%	<b>Social Network size</b> (Network Interview)	<b>None</b>

Study Country	Sample size	Function Rel. Entry Criteria	Control Group	Provider	Context	BME (%)	Empl'y'd (%) <sup>1</sup>	Objective Outcome	Subjective Outcome
<b>RECOVERY AND REHABILITATION THERAPIES</b>									
<b>12</b> Bitter et al. (2017)  <i>Netherlands</i>	N = 152 (Int. = 41 Cont. = 111)	None	TAU	Support workers in a housing support service for people with SMI, mental health treatment provided by local MHTs	Semi urban	NR	57%	None	<b>QoL (P) (MANSA), Social Functioning (SFS), Recovery (MHRM)</b>
<b>13</b> Fowler et al. (2009)  <i>UK</i>	N = 67 (Int. = 35 Cont. = 32)	Less than 16 hrs of paid work / education per week	TAU	CBT therapists working out of mental health teams	Urban/rural mix	9%	0%	<b>Structured activity (P) (TUS)</b>	<b>QoL (QLS) Social Functioning (SOFAS)</b>
<b>14</b> Fowler et al. (2019)  <i>UK</i>	N = 154 (Int. = 75 Cont. = 79)	Non affective psychosis only, less than 30 hours of structured activity a year	TAU	CBT therapists working in an EIPs	Multi-site trial including EIPs working in both urban and urban/rural settings	23%	NR	<b>Structured activity (P) (TUS)</b>	

Table 1: List of studies included. *Note Davidson et al. 2004 appears twice due to having two arms of an RCT, one with peer support and one with befriending. Rivera et al. (2007) had two control groups, but only the standard care control group is included in this review.*

<sup>1</sup>Employment can be paid employment, voluntary employment, or sheltered employment, full or part time.

NR= Not Reported MHT = mental health team, EIPS = Early Intervention for Psychosis Service, TAU= treatment as usual, QoL= Quality of Life, P= primary outcome, TUS = time use survey, SCA = social contact assessment, LQoL = Lehman's quality of life checklist, MSLQ = modular system of quality of life, MANSA = Manchester Short Assessment of Quality of Life, QLS = Quality of Life Scale, SFS = Social Functioning Scale, SOFAS = Social and Occupational Functioning Assessment, MHRM = Mental health Recovery Measure.

### **3.3 Interventions and Core Components**

Four types of intervention were identified; peer support, befriending, shared activity, and recovery and rehabilitation therapies. These interventions are described below using the core components extracted from the included studies.

#### **3.3.1 Peer support**

Peer support is an intervention whereby members of the community, with a history of mental health difficulties, are recruited into, or to work alongside, mental health teams. Their role is to engage service users through the provision of personalised, flexible, and intensive support (Felton et al., 1995; Rivera et al., 2007; Mahlke et al., 2017), with the aim of supporting the service user to build and maintain relationships, access community resources, and establish motivation and hope (Klein et al., 1998; Craig et al., 2004; Rivera et al., 2007; Chinman et al., 2015; Mahlke et al., 2017).

The core components are threefold. Firstly, the peer supporter acts as a conduit to broad, socially embedded social networks (Felton et al., 1995; Klein et al., 1998; Rivera et al., 2007). Secondly, they can describe and demonstrate strategies of coping with the challenges of social engagement (Felton et al., 1995; Klein et al., 1998; Craig et al., 2004; Chinman et al., 2015; Mahlke et al., 2017). Finally, they provide a model for social recovery (Klein et al., 1998; Rivera et al., 2007).

There is a debate as to how closely involved with the day-to-day work of the mental health team the peer supporter should be. Some, e.g. Mahlke et al. (2007), argue that they should remain separate from the team to maintain their focus on social recovery whereas others, e.g. Chinman et al. (2015), argue that they have a role in promoting social recovery within the team.

#### **3.3.2. Befriending**

Befriending is an intervention whereby members of the community volunteer to spend time with service users engaging in community activities with money provided by the supporting institution. The relationship lasts between 9 months and a year with expected contact of between 1 and 4 hours a week. Volunteers are supervised within health services, or supporting



institutions, but are completely separate from the mental health team (Davidson et al., 2004; Priebe et al., 2020; Sheridan et al., 2015).

The core components are twofold. Recruiting members of the wider community to build relationships with service users provides direct access to broad, socially embedded, relationship networks (Davidson et al., 2004; Sheridan et al., 2015). Secondly, the development of these relationships breaks down stigma, including the service user's internalised stigma, which contributes to social exclusion (Priebe et al., 2020)

### **3.3.3 Shared activities**

As with befriending, shared activities create opportunities for service users and the wider community to meet and build relationships, but this is done through engaging in an activity such as learning skills. Only one such intervention met the criteria for the current review, a university based social skills class running for 3 hours a week, for 15 weeks (Stein et al., 1995). As with befriending the core components are access to social networks and reducing stigma. However, shared activity interventions recognise the overlap between the learning needs of people with SMI and the wider community which provides an opportunity for collaborative work towards a shared goal. This provides a non-stigmatised environment for relationship building and is shown to increase wellbeing for both groups (Stein et al., 1995).

### **3.3.4 Recovery and Rehabilitation therapies**

Some recovery and rehabilitation therapies specify that, alongside the established therapeutic tasks, the therapist intervenes in a service user's community to support them to establish socially valued roles. This can be achieved through a process akin to supported employment whereby the professional meets with the service user in the community alongside important community actors such as colleagues, managers, and educators (Fowler et al., 2009; Fowler et al., 2018), or more flexibly whereby the professional is tasked with 'improving access to the desired environment and to create support within the society' (Bitter et al., 2017). This can be structured with weekly, time limited, sessions, e.g. Fowler et al. 2009, or can be more flexible and open ended, e.g. Bitter et al. 2017.

The core components are that people with SMI are motivated to take up roles in the community but lack the skills and confidence to do this. However, skills and confidence are more likely to take hold if they are practised and supported in vivo. Members of the community are able to provide the required scaffolding if they too are supported (Bitter et al., 2017; Fowler et al., 2009, 2018).

### **3.4 Outcome Measures**

#### **3.4.1 Objective measures**

Three studies (2,7,11) (*see table 1*) used a measure of social network size using semi structured interviews referred to as ‘network interviews’, in which participants are asked to list people that they consider to be important to them in some way. One study (7) estimated number of contacts using a network interview and one (9) asked people to list the people that had been in contact within the previous four days, outside of the workplace, home, or health care setting.

Three studies (9,13,14) used an adapted time use survey (TUS) (Hodgekins et al., 2015) in which participants are asked how long they have participated certain activities, for example work, childcare and leisure and hobbies, in the past month.

One study (7) used an objective outcome index (Priebe et al., 2008) which measured the presence or absence of important social outcomes; paid employment, independent accommodation, living with partner or family, and meeting a friend in the last week.

#### **3.4.2 Subjective measures**

Five studies (2, 3+8,10,12,14) used measures of social function. Three studies (3+8,10,12) used the Social Functioning Scale (SFS) (Birchwood et al., 1990) as a self-report measure asking participants about frequency, structure, and competence, of their social activity. One study (13) used the Social and Occupational Functioning Scales (SOFAS) (Goldman et al., 1992) and one (2) the social connection subscale of the Life Skills Profile (LSP) (Rosen et al., 1989), both of which ask clinicians to rate degree of social impairment.

Five studies (1,6,9,12,13) used composite quality of life scales, Manchester Short Assessment of Quality of Life (MANSA) (Priebe et al., 1999), Quality of Life Brief Instrument (Lehman et al., 1989), Modular System of Quality of Life (Pukrop, 2003), and The Quality of Life Scale (QLS) (Heinrichs et al., 1984). All of these instruments ask participants how satisfied they are in all areas of their life including relationships, employment, living situation, and health.

Three studies (4,5,7) used Lehman's quality of life checklist (Lehman, 1988) which does not have a composite score. Data from social relations / friendship subscale were extracted as the scale most relevant to the purposes of this review. One study (2) measured relationship satisfaction using a semi structured network interview.

Two studies (1,12) used the Mental Health Recovery Measure (MHRM) (Bullock & Young, 2003), alongside measures of quality of life and social functioning. The MHRM measures psychological variables; spirituality, empowerment, and learning. These outcomes were considered to deviate considerably from social functioning and were subsequently not included.

### **3.4.3 Study quality**

See appendix two for the full quality checklist for the included studies. Studies were given a percentage score for presence or absence of the 28 study quality characteristics. Scores ranged from 39% to 89% with an average of 69%. The higher quality studies were generally differentiated from the lower quality studies by the presence of power calculations, randomisation concealment, and accounting for loss to follow up in the statistical analysis. The lowest quality studies were less likely to carry out measurement blinding and to describe how representative recruitment was.

## **3.5 Outcomes**

### **3.5.1 Peer Support**

Seven studies (1-7) measured the impact of peer support, five of these were in the USA and two were in Europe. All but two of the interventions, Davidson et al (2004) and Mahlke (2017), recruited peer supporters to work as part of the mental health team. Mahlke et al. (2017)

evaluated a team of peer supporters, attached to a mental health team, but working separately. Davidson et al. (2004) evaluated a volunteer-based intervention run separately from mental health services. All mental health teams were based in inner city, with all but one, Mahlke (2017), catering for people with especially high levels of psychiatric disability, for example multiple recent hospital admissions, or poor engagement with services (see table 1). Davidson et al. (2004) volunteer programme catered for people across and urban and rural area, with no requirement for especially high levels of psychiatric disability or poor engagement.

All studies used a subjective measure of social functioning, either a social functioning scale (1, 3), or a measure of quality of life (1,2,4,5,6,7). None were the designated primary outcome measure of the study. Of these, only one, Craig et al (2004) a study of moderate quality, reported a statistically significant effect in favour of the intervention, using the social contact subscale on the LSP (Rosen et al., 1989). (Tables 2 -3)

Two studies (2,7) used objective measures of social functioning. Neither Riveria (2007) nor Craig (2004) observed an increase in participants' social network size (Table 4), however Rivera (2007) report a large and statistically significant increase in the frequency of social contact across the study period (Table 5). The authors report that this was accounted for by increases in contact with mental health services precipitated by peer involvement.

### **3.5.2 Befriending**

Three studies (8-10) evaluated befriending interventions. One particularly high-quality study, Priebe et al (2020), reported a statistically significant increase of 0.53 social contacts in the previous four days, at 12 months, and 0.73 at 18 months in favour of the intervention group (Table 8). There was also an accompanying increase in a composite objective outcomes measure (Table 10) which was driven by the item 'have you met a friend in the last week?' (Priebe et al., 2020). This intervention recruited participants meeting a threshold of less than 60 minutes structured activity a day, from an inner-city area. Despite this being a high-quality study, these two outcomes were not designated primary outcomes and this secondary analysis was of a lower quality. Loss to follow up was not adjusted for and an overall group by time statistical model was not provided. The primary outcome was time use for which there was no difference between groups at 12 months (Table 9). This study also used a subjective

measure of function, quality of life, which did not differ between groups at 12 months (tables 6-7).

Two studies of lower quality, Sheridan et al (2015), and, Davidson et al. (2020) used the subjective, social functioning scale (SFS), but neither demonstrated statistically significant differences between groups (tables 6-7).

### **3.5.3 Shared activity**

A single (11), poor quality, evaluation of a shared activity intervention met the inclusion criteria for this review. This is an evaluation of a social skills training class in a university in the USA that was open to both students and users of a local mental health centre (Stein et al., 1995). A network interview measured social network size at the start and end of the 15-week intervention, but no statistical analysis was performed on this difference. There appears to be no effect of the intervention, with social network size reducing in those in the intervention group and remaining the same in the control group (Table 11).

### **3.5.4 Recovery and Rehabilitation Therapies**

Three studies (12-14) report on recovery, or rehabilitation, therapies. Two of these studies are multi-centre evaluations of Social Recovery Therapy (Fowler et al. 2009; Fowler 2018) delivered by CBT therapists in mental health teams in the UK, and one is a cluster evaluation, the Comprehensive Rehabilitation Approach (CARE), (Bitter et al. 2017) delivered by housing support teams in the Netherlands. Social Recovery Therapy was delivered as an adjunct to treatment as usual with participants required to have meet a threshold for functional disability, less than 16 hours a week of employment or education (Fowler 2009) or less than 30 hours a week of structured activity (Fowler 2018). Both studies required participants to be in the early stages of their mental health difficulties, 8 years or less (Fowler et al. 2009) and 3 years or less (Fowler et al. 2018). CARE is an enhanced method of delivering mental health recovery support, provided by each team member, and available to all service users, on an ongoing basis. The participants are a relatively high functioning group with over 50% in some form of employment at the start of the study.

The social recovery evaluations were both of high quality, using objective methods of social functioning, the TUS, as the primary outcome (Table 14). Fowler et al. (2009) also report subjective measures of function; both quality of life, and social functioning (Tables 12-13). Despite initially demonstrating no statistically significant effect for any measure of social functioning in a mixed sample of participants with affective and non-affective psychosis, Fowler et al. (2009) report a planned subgroup analysis of just the non-affective group demonstrating a statistically significant increase of 8 hours structured activity per week in favour of the intervention group at 9 months. However, neither the measure of QOL or social functioning demonstrate any difference in this subgroup analysis. This effect on structured time use for people with non-affective psychosis is replicated by Fowler et al. (2018), again demonstrating an increase of 8 hours structured activity per week. However, this effect of the intervention is not maintained post intervention with activity dropping off in the intervention group and continuing to rise in the control group.

The evaluation of the CARE methodology, a study of moderate quality, uses both a measure of quality of life, the primary outcome measure, and social functioning (Tables 12 – 13). However, there are no differences between groups on either measure when considered across the 20 months of the evaluation.

## 4 Discussion

This review sought to assess effectiveness of interventions in which mental health services engage members of the wider community to support people with severe mental illness (SMI) towards social recovery. It was proposed that these interventions would facilitate social recovery by providing access to the social capital inherent in the social networks of mental health services. Thirteen studies were identified covering four types of intervention; peer support, befriending, shared activity, and social recovery therapy or rehabilitation. Eight of the interventions were provided by the mental health team and five were provided by supporting institutions, three used volunteer services, one a supported housing project, and one a university department. The relationships between mental health teams and community-based institutions such as these are common in developed health care systems, for example in the collaboration between mental health services and universities in the training mental health professionals and the developing role of voluntary sector organisations in supporting and enhancing the provision of statutory care in the UK (for example see Wardle, 2021). Therefore, all the interventions identified appear to be within the scope of such developed health care systems.

Both befriending and peer support interventions identify the restricted access to social networks and valued social roles, experienced by many people with SMI, as a key barrier to recovery. A putative active component of these interventions is the role of the peer, or community volunteer, in bridging the gap to broader, more embedded, social networks. Befriending and shared activity both identify stigma as a process driving social exclusion and seek to address this by providing the space for people with SMI and those from the wider community to meet and develop relationships. Stigma was addressed uniquely in the shared activity intervention, in the recognition that shared learning removed the carer and cared-for distinction. All the interventions, apart from befriending, placed a heavy focus on the nurturing of skills and strengths that can be done through the development of relationships with the wider community.

Peer interventions suggest that there is a way of being in the world, and managing symptoms of psychiatric ill health, that can be transmitted from peer to peer through discussion and modelling. Social Recovery Therapy and the CARE rehabilitation approach used standardised approaches to building skills but emphasised in vivo practice in a nurturing environment. None of the interventions discussed the role of social capital as an active ingredient in the intervention.

This review provides preliminary evidence that recruiting members of the wider community could have an impact on both frequency of social contacts and structured time use for people with SMI. Frequency of social contact increases when members of the community volunteer to befriend service users (Priebe et al., 2020), and structured time use increases when service users are supported to engage in valued community roles, such as employment, alongside a focused therapeutic intervention (Fowler et al., 2009, 2018). These results should be understood with the caveat that other befriending and structured rehabilitation interventions demonstrated no effect on measures of social function and quality of life, meaning that the evidence for their effectiveness is currently unclear. However, these three studies are distinct from similar evaluations in important ways which may explain the positive findings. Firstly, it is notable that they were of the highest quality in the review which may have contributed to their positive results. Secondly, these studies focused on a subset of people with SMI who are more functionally impaired on average and, in the case of social recovery therapy, at an earlier stage of their mental health difficulties. This suggests that engaging the wider community to support those with SMI may be most effective in improving function for those most impaired at baseline. This is an important finding adding to the evidence base of interventions for people that are the most difficult to support. However further investigation needs to be done on how to help those with better functioning who may still feel dissatisfied with their ability, and opportunity, to engage in their community. Finally, these three studies set themselves apart from the other studies in the review by focusing on objective measures of function. Given that both Priebe et al. (2020) and Fowler et al. (2009) demonstrate changes on objective measures, but not subjective measures, of social recovery, it seems that measures such as structured time-use and social contact frequency may be more sensitive to real world changes in participants' experience than instruments measuring the constructs of social function and QOL. In terms of measures of social function this finding supports evidence, using experience sampling methodology, on the divergence between subjective measures of social function and the day to day experience of people with SMI (Schneider et al., 2017) as well as evidence that social functioning as a construct may have limited validity and reliability (Whitaker, 2013). This finding may also reflect similar difficulties in the construct of QOL. However, disparities between changes on objective measures of function and changes on instruments of QOL may reflect a stability of satisfaction appraisals despite changes to an individual's social environment.



In this current review there is little evidence for the role of peer supporters or shared activity in improving social functioning for people with SMI. However, there may be other factors contributing to this finding. None of the peer support or shared activity interventions identified functional change as a primary outcome of interest and mostly relied on subjective measures of function. The only study of shared activity was small and of very poor quality.

The relative impact of social capital may also explain some of the differences in findings. Both interventions of promise; befriending and social recovery therapy, create opportunities for service users to build roles and relationships away from the mental health system. The peer supporter interventions, where the relationship with the peer is very much part of the work of the mental health team, do not offer this same distance. Bourdieu suggests that all social activities take place in 'fields' of predetermined relationship structures and rules of engagement which limit the ways that individuals are able to acquire and use capital (Siisiainen, 2003). By entering a 'field' dominated by the mental health service, users will be forced to take on the roles determined by it. For users of the service this is likely to entail a 'sick' role (Parsons, 1951) which is a stigmatised social position, especially for those with SMI (Angermeyer & Dietrich, 2006), and likely to limit access to all forms of capital, social and otherwise.

## **5. Conclusions**

### **5.1 Relative Strengths and Limitations**

This systematic review addressed an area of high clinical relevance, social functioning in people with SMI, and how this can be tackled using the resources currently available to mental health services. The review used a novel approach, leveraging the social capital of mental health teams, to address this. Social capital was clearly defined, as the development of relationships to the wider community. Consequently, two interventions of promise, befriending and social recovery therapy, have been identified to support those with the greatest impairment of function.

However, this review attempted to be both broad, looking for all types of interventions in which mental health teams engage members of the wider community, and specific, evaluating the effects of these interventions on social function. This focus on specificity limited the breadth of reports that could be included and meant some very creative and interesting interventions were left out because they did not have a control group or were focused on a broader range of service users. A related limitation was that, whilst hypothesising that access to social capital may play a role in the improvement of social functioning, the impact of the interventions on social capital itself was not explored as it is rarely used as an evaluation measure. Therefore, the role of social capital in the relationship between the interventions and social functional outcomes remains hypothetical.

Finally, although this review has led to the development of some interesting hypotheses, it has uncovered a limited amount of high-quality evidence meaning that no firm conclusions can be made on the impact of the interventions on social function.

### **5.2 Clinical and Research Implications**

This review provides preliminary and limited support for the impact of befriending and social recovery therapy in supporting services users towards social functional recovery. Given that these interventions use resources generally available to mental health teams, CBT therapists and relationships with volunteer agencies, their implementation should be considered for

people with higher levels of functional impairment. When considering social recovery therapy, the CBT therapists should be given time and training to enable them to carry out the therapy as designed, and the intervention should be prioritised for those in the early stages of their mental health difficulties.

Further work is needed on understanding the relationship between social capital, the social networks of mental health teams, and interventions that could have an impact on function of all service users with SMI, not just the most functionally impaired. Therefore, a scoping review focusing on the breadth of interventions, and the way that social capital may be operationalised within them, would be of great interest.

Finally, this review provides further evidence that subjective measures of social functioning, such as social functioning scales and instruments of quality of life, may be less sensitive to changes in the day-to-day experiences of those taking part than objective measures. These changes are often highly valued by range of stakeholder groups and provide data that enables the potential strengths of an intervention to be easily interpreted (Priebe, 2007). Therefore, objective measures of function seem to demonstrate considerable strengths in the evaluation of mental health care interventions and can operate as effective primary outcome measures.

# QUALITY OF LIFE (QoL)

PEER SUPPORT											
Quality of Life (QoL)		Study Qual	RCT	Base-line	Follow up One			Follow up Two			Intervention x time <sup>1</sup>
						Effect	P-value		Effect	P-value	Effect
1	<b>Chinman et al. 2015</b> Quality of life brief instrument	86%	Y Cluster	Int. 4.64 (1.04) Cont. 4.54 (1.03)	12 mnths 4.72 (1.04) 4.71 (0.90)	z score 0.03	p=0.98				
2	<b>Craig et al. 2004</b> Network interview	61%	Y	Int. 4.5 (1.1) Cont. 5.3 (0.8)	12 mnths 4.8 (0.9) 5.3 (0.6)		ns				
4	<b>Felton et al. 1995</b> Lehman's QoL checklist social rels' subscale	61%	N	Int. 4.12 Cont. 3.83	4.18 3.81		ns				
5	<b>Klein et al. 1998</b> Lehman's QoL checklist friendship subscale	54%	Y	Int. 3.58 Cont. 3.71	18 mnths 3.71 3.37		p> 0.05				
6	<b>Mahlke et al. 2017</b> Modular system of QoL	79%	Y	Int. 20.7 (5.69) Cont. 20.4 (4.95)	6 mnths 23.8 (7.32) 23.6 (6.92)			12 mnths 25.9 (6.75) 23.7 (6.79)			AMD 0.11 (-1.83 to +2.05)
7	<b>Rivera et al. 2007<sup>2</sup></b> Lehman's QoL checklist social rels' subscale	64%	Y	Int. 4.6 (1.1) Cont. 4.8 (1.1)	4.8 (1.1) 4.9 (1.3)			4.9 (1.0) 5.0 (1.2)		ns	

**Table 2:** Outcomes of peer support studies reporting quality of life. <sup>1</sup> = adjusting for multiple follow-ups <sup>2</sup> = Rivera et al report two control groups but only standard care reported here

AMD=adjusted mean difference, ns= not significant.

## SOCIAL FUNCTIONING

PEER SUPPORT										
Social Functioning		Study Qual	RCT	Base-line	Follow up One			Follow up Two		
					Effect	P-value		Effect	P-value	Intervention x time <sup>1</sup>
										Effect P-value
2	<b>Craig et al. 2004</b> Life skills profile, social contact scale	61%	Y	Int. 13.9 (3.7) Cont. 17.5 (3.4)	15.6 (3.8) 15.3 (3.6)	p=0.005				
3	<b>Davidson et al. 2004</b> Social Functioning Scale	57%	Y	Int. 124.74 (23.17) Cont. 129.01 (22.61)	125.82 (21.85) 127.49 (24.43)			124.80 (21.93) 127.29 (23.25)		ns

**Table 3:** Peer support intervention reporting social functioning. <sup>1</sup> = adjusting for multiple follow-ups ns = not significant

## SOCIAL NETWORK SIZE

PEER SUPPORT										
Social Network Size		Study Qual	RCT	Base-line	Follow up One			Follow up Two		
					Effect	P-value		Effect	P-value	Intervention x time <sup>1</sup>
										Effect P-value
2	<b>Craig et al. 2004</b> Network interview	61%	Y	Int. 4.8 (2.4) Cont. 5.4 (2.9)	12 mnths 7.8 (3.8) 7.5 (4.7)	ns				
7	<b>Rivera et al. 2007<sup>2</sup></b> Network interview	64%	Y	Int. 11.2 (4.5) Cont. 11.0 (4.7)	6 mnths 11.8 (4.2) 11.0 (4.3)			12 mnths 12.1 (4.3) 11.0 (4.7)		ns

**Table 4:** Peer support interventions reporting social network size <sup>1</sup> = adjusting for multiple follow-ups <sup>2</sup> = Rivera et al report two control groups but only standard care reported here ns= not significant

## No. OF CONTACTS

PEER SUPPORT										
Number of Contacts		Study Qual	RCT	Base-line	Follow up One			Follow up Two		
					Effect	P-value		Effect	P-value	Intervention x time <sup>1</sup>
										Effect P-value
7	<b>Rivera et al. 2007<sup>2</sup></b> Network interview	64%	Y	Int. 29.9 (15.7) Cont. 29.1 (16.1)	6 mnths 36.6 (14.3) 28.8 (16.6)			12 mnths 37.4 (17.4) 29.6 (13.2)		η <sup>2</sup> 0.11 p<0.01

**Table 5:** Peer support interventions reporting number of social contacts (last 2 months) <sup>1</sup> = adjusting for multiple follow-ups <sup>2</sup> = Rivera et al report two control groups but only standard care reported here

## QUALITY OF LIFE

BEFRIENDING										
	Quality of Life (QoL)	Study Qual	RCT	Base-line	Follow up One			Follow up Two		
					Effect		P-value	Effect		P-value
9	<b>Priebe et al. 2020</b> Manchester short assessment of QoL	86%	Y	Int. 4.26 (0.92) Cont. 3.98 (1.10)	12 mnths 4.45 (1.0)	AMD 4.31 (0.83)	0.00 (-0.31 to +0.31)	ns		

**Table 6** Befriending interventions reporting quality of life <sup>1</sup> = adjusting for multiple follow-ups AMD= adjusted mean difference ns= not significant

## SOCIAL FUNCTIONING

BEFRIENDING										
Social Functioning		Study Qual	RCT	Base-line	Follow up One			Follow up Two		
					Effect		P-value	Effect		P-value
3	<b>Davidson et al. 2004</b> Social Functioning Scale (SFS)	57%	Y	Int. 122.08 (23.55) Cont. 129.01 (22.61)	6 mnths 126.24 (22.76)			12 mnths 128.44 (24.69)		ns
10	<b>Sheriden et al. 2015</b> Social Functioning Scale (SFS)	68%	Y	Int. 100.4 (15.0) Cont. 99.7 (15.1)	4 mnths 108.0 (15.0)			10 mnths 104.1 (23.4)		p = 0.55

**Table 7** Befriending intervention reporting social functioning <sup>1</sup> = adjusting for multiple follow-ups ns= not significant

## No. OF CONTACTS

BEFRIENDING										
Number of Contacts		Study Qual	RCT	Base-line	Follow up One			Follow up Two		
					Effect		P-value	Effect		P-value
9	<b>Priebe et al. 2020</b> Social contacts assessment	86%	Y	Int. 1.56 (2.59) Cont. 1.33 (1.69)	12 mnths 1.88 (2.00)	AMD 0.52 (0.04 to 0.99)	p<0.05	18 mnths 4.03 (6.59)	AMD 0.73 (0.05 to 1.4)	p<0.05

**Table 8** Befriending interventions reporting frequency of social contacts (last 4 days) <sup>1</sup> = adjusting for multiple follow-ups, AMD = adjusted mean difference

## TIME USE SURVEY

BEFRIENDING										
Time Use Survey		Study Qual	RCT	Base-line	Follow up One			Follow up Two		
					Effect		P-value	Effect		P-value
9	<b>Priebe et al. 2020</b>	86%	Y	Int. 20.03 (21.05) Cont. 17.41 (19.99)	12 mnths 81.29 (18.43)	AMD 70.33 (15.72)	8.9 (-40.69 to +58.50)	p=0.72		

**Table 9** Befriending interventions reporting structured time use <sup>1</sup> = adjusting for multiple follow-ups, AMD=adjusted mean difference

## OBJECTIVE OUTCOMES INDEX

BEFRIENDING											
Objective outcomes index		Study Qual	RCT	Base-line	Follow up One			Follow up Two			Intervention x time <sup>1</sup>
						Effect	P-value		Effect	P-value	Effect
9	Priebe et al. 2020	86%	Y	Int. 2.55 (0.99) Cont. 2.61 (0.79)	12 mnths 2.86 (0.93) 2.66 (1.25)	AMD 2.45 (1.06 to 5.67)	p<0.05	18 mnths 2.90 (0.99) 2.67 (1.24)	AMD 3.05 (1.13 to 8.20)	p<0.05	

**Table 10** Befriending Interventions reporting an Objective Outcomes Index <sup>1</sup> = adjusting for multiple follow-ups, AMD=adjusted mean difference.

## SOCIAL NETWORK SIZE

SHARED ACTIVITY											
Social Network size		Study Qual	RCT	Base-line	Follow up One			Follow up Two			Intervention x time <sup>1</sup>
						Effect	P-value		Effect	P-value	Effect
11	Stein et al. 1995 Network interview	39%	N	Int. 12.3 Cont. 10.5	4 mnths 10.2 10.8						

**Table 11:** Shared activity intervention reporting social network size <sup>1</sup> = adjusting for multiple follow-ups

## QUALITY OF LIFE

RECOVERY AND REHABILITATION THERAPIES											
Quality of Life (QoL)		Study Qual	RCT	Base-line	Follow up One			Follow up Two			Intervention x time <sup>1</sup>
						Effect	P-value		Effect	P-value	Effect
12	Bitter et al. 2017 Manchester Short Assessment of QoL	68%	Y Cluster	Int. 4.08 (0.70) Cont. 3.93 (0.67)	4.15 (0.66) 3.89 (0.77)	Cohen's d 0.373	p=0.01	4.57 (0.95) 4.53 (0.75)	Cohen's d 0.051	p=0.74	p=0.11
13	Fowler et al. 2009 Quality of life scale (QLS)	89%	Y	Int. 66.8 (14.8) Cont. 62.7 (14.8)	76.1 (14.0) 72.5 (18.5)		ns				

**Table 12:** Recovery and Rehabilitation Therapies reporting quality of life <sup>1</sup> = adjusting for multiple follow-ups ns=not significant

## SOCIAL FUNCTIONING

RECOVERY AND REHABILITATION THERAPIES											
Social Functioning		Study Qual	RCT	Base-line	Follow up One			Follow up Two			Intervention x time <sup>1</sup>
						Effect	P-value		Effect	P-value	Effect
12	<b>Bitter et al. 2017</b> Social Functioning Scale (SFS)	68%	Y Cluster	Int. 112.13 (24.76) Cont. 109.57 (23.21)	10 mnths 107.86 (26.92) 108.57 (23.89)	Cohen's <i>d</i> -0.028	0.81	20 mnths 111.78 (22.93) 115.87 (24.96)	Cohen's <i>d</i> -0.17	0.26	0.1
13	<b>Fowler et al. 2009</b> Social & Occupational Functioning Scale (SOFAS)	89%	Y	Int. 51.5 (9.0) Cont. 48.9 (7.9)	9 mnths 54.8 (9.4) 53.8 (12.3)		ns				

**Table 13** Recovery and Rehabilitation Therapies reporting social function <sup>1</sup> = adjusting for multiple follow-ups ns= not significant

## TIME USE SURVEY

RECOVERY AND REHABILITATION THERAPIES											
Time Use Survey		Study Qual	RCT	Base-line	Follow up One			Follow up Two			Intervention x time <sup>1</sup>
						Effect	P-value		Effect	P-value	Effect
13	<b>Fowler et al. 2009</b>	89%	Y	Int. 30.4 (19.9) Cont. 27.9 (19.2)	9 mnths 40.0 (22.8) 34.4 (20.6)		ns				
14	<b>Fowler et al. 2019</b>	89%	Y	Int. 12 (8.6) Cont. 11 (7.5)	9 mnths 26.6 (24.2) 18.8 (20.0)	AMD 8.08 (2.502 to 13.657)	p=0.005	15 mnths 23.0 (19.0) 22.5 (23.3)	AMD 0.054 (-5.154 to +5.262)	p=0.98	

**Table 14** Recovery and Rehabilitation Therapies reporting structured time use <sup>1</sup> = adjusting for multiple follow-ups

AMD= adjusted mean difference NS=not significant



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## **Chapter 2 – Empirical Paper**



# Psychosis, the Covid-19 Pandemic, and Wellbeing

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## **Abstract**

**Background:** The unusual experiences inherent in psychosis are related to an individual's wellbeing as well as their environment. The rapid changes in the social and psychological environment precipitated by the Covid-19 pandemic created an opportunity to explore the evolution of this relationship.

**Method:** A narrative analysis was conducted on the accounts of the first year of the Covid-19 pandemic given by five people living with psychosis in North Wales, United Kingdom.

**Results:** Experiences of wellbeing and distress varied considerably between participants, and across time. Access to physical and psychological space, and social support, improved wellbeing. Participants described a struggle between maintaining a coherent sense of self and a connection to others which fluctuated with the changes brought about by the pandemic.

**Conclusion:** The pandemic should be seen as series of changes that people with psychosis have had to adapt to, some more successfully than others. The struggle to maintain a coherent sense of self is a key aspect of psychosis and, for some, retreat appears to be of benefit as part of this struggle. The detailed close-up narratives illustrated the resilience and perseverance of these individuals which is not always recognised in other forms of research.

**Declaration of Interest:** No financial or benefit has arisen from the direct application of this research

**Keywords:** Psychosis, Wellbeing, Covid-19, Narrative, Self, Relationships, Reality, Qualitative, Retreat, Control,

## 1. Background

Psychotic disorder is a term given to a range of experiences which include voice hearing, holding strong beliefs that others do not share, and persistent difficulties with focus, motivation and functioning. Psychotic disorder has an international prevalence of 26.6 per 100,000 (Jongsma et al., 2019). The relationship between the concept of individual ‘wellbeing’, and the unusual experiences and beliefs that make up the experience of psychosis is of interest. Individual wellbeing has been defined psychologically as existing along six continua; self-acceptance, environmental mastery, positive relations to others, autonomy, sense of purpose, and psychological growth (Ryff, 1989). There appears to be two-way relationship between aspects of wellbeing and the experiences of psychosis. Firstly poor wellbeing increases the frequency and nature of psychotic experiences, for example struggles with self-acceptance, environmental mastery, and positive relations to others are associated with frequency and valence of unusual beliefs and experiences (Birchwood et al., 2000; Fowler et al., 2012). Likewise physiological and emotional dysregulation in response to environmental stressors has been shown to contribute to the expression of psychosis (Pruessner et al., 2017).

However psychotic experiences may also help promote wellbeing. An individual’s beliefs about the world are influenced by their subjective hopes and desires, we see the world as we want it to be (Warman & Martin, 2006). Considered in this way an unusual belief is a reflection of an individual’s hopes and fears and can actually be a way of making a sense of the world that promotes a sense of control, purpose, and self-esteem (Roberts, 1991). This suggests that some psychotic experiences may enhance wellbeing, perhaps in response to a world that an individual finds undermining, threatening, and controlling, or in response to difficulties with emotional regulation. Certainly at a population level it has been shown beliefs that are extreme and paranoid but that offer a locus of control, for example the stigmatisation of certain groups, are more prevalent at times of crises and uncertainty (van Prooijen & Douglas, 2017).

Therefore, a relationship between wellbeing and experiences of psychosis can be postulated, with unusual experiences and beliefs evolving over time in response to periods of stress and discomfort. Whilst unusual experiences may act, at points, to stabilise some aspects of wellbeing there is also a cost. Unusual experiences entail a divergence from shared reality, and therefore a sense of connection to other people, which can in turn exacerbate stress and

discomfort (Griffiths et al., 2019). This putative relationship between wellbeing and the experience of psychosis is therefore complex, with symptoms of psychosis both offering opportunities for wellbeing whilst at the same time acting as barrier. This relationship is likely to be further complicated by the idiosyncrasies of experience amongst people with psychosis. For example, for some people psychosis is an experience that needs to be escaped from, or endured, whereas others see it as a process of enlightenment (Thornhill et al., 2004; Marriott et al., 2019). This suggests that the wellbeing opportunities that psychotic experiences provide are more available to some than others.

Finally, the context in which an individual finds themselves is likely to influence the relationship between experiences of psychosis and wellbeing. For example, the operation of stigma and disempowerment (Corrigan & Watson, 2002) are likely to restrict opportunities for wellbeing promotion. Again however, people with psychosis are also first and foremost people, with their own contexts and related tastes and preferences that inform and constrain their choices on how they maintain and enhance their wellbeing. For example Andersson et al (2015) demonstrated that for some, socially isolated, people with psychosis, isolation was a preference based on their current life circumstances and goals. Whereas for others isolation was enforced through factors only tangentially related to their mental health, for example unemployment, rather than directly due to their symptoms.

The Covid-19 pandemic has offered a unique opportunity to further explore this relationship between context, experiences of psychosis, and wellbeing. With over 156 million cases and 3.25 million deaths to date, Covid-19 is one of the most far reaching and deadliest pandemics in global history. As the spread of the virus has increased, and then receded, only to increase again, human societies have experienced rapid changes. Specifically, living with fluctuations in the prevalence of an invisible and deadly threat, and managing the imposition and lifting of highly restrictive physical distancing measures that have had huge implications for human interaction.

To date investigations into the impact of the pandemic on symptoms in groups of people with pre-existing mental health problems present a mixed picture. There are reports of worsening symptoms for some, but not all, participants (see Murphy et al. 2021 for review) and there are also reports of symptom improvement (Baenas et al., 2020; Hamza et al., 2021). Contextual factors such as isolation, stressors, and access to social support (Asmundson et al., 2020; D.

Murphy et al., 2020) have been shown to mediate this relationship between experience of the pandemic and symptom change. Likewise subjective wellbeing, for example having effective coping strategies (Asmundson et al., 2020; Gobbi et al., 2020; O'Connor et al., 2021), has also been shown to mediate this relationship. In terms of serious mental illness and psychosis, two longitudinal studies demonstrated no change when comparing the symptoms prior to the pandemic to just after the first stay at home orders were introduced (Pinkham et al., 2020; Riblet et al., 2020). One of these studies suggested that whilst symptoms did not change participants' wellbeing increased over this time period, an increase that was strongly associated with spending less time alone (Pinkham et al., 2020). However, a qualitative-analysis demonstrated that spending time with others is a nuanced concept with some participants reporting benefits from reduced social contact (Riblet et al., 2020). Finally Ma et al. (2020) found increased symptoms in those with schizophrenia who had been forced to isolate compared to those that had not.

These studies give a preliminary understanding of the relationship between pandemic related changes, wellbeing, and symptoms of psychosis. Firstly, assumptions that mental health symptoms have necessarily increased as a consequence of the pandemic are misplaced. Secondly, as predicted by the model outlined above, an individual's context and opportunities for wellbeing are likely to have played an important role in the relationship between the pandemic and symptoms. Finally, individual experiences, and the interpretation of these experiences, mean that this relationship between the pandemic and symptoms is likely to be relatively idiosyncratic. Further investigation into the experiences of people with psychosis during the Covid-19 pandemic is therefore required. Firstly, to date, very little of the research has been on psychosis. Given the unique relationship between the symptoms of psychosis and a shared social reality, extrapolations from research into other disorders is of limited utility. Secondly the limited time frame of the research to date means that it has not captured the fluctuating nature of the pandemic. Finally, most of the research has been quantitative and has not been able to capture the subjective and idiosyncratic aspect of the experience of psychosis. This study aimed to build on, and develop, the existing research base by analysing the narratives, told by people with psychosis, of their experience of the Covid-19 pandemic up to February 2021.

## **1.2 Research Questions**

- 1) What happened to people with psychosis during the Covid-19 pandemic, how did their lives and their mental health change over this time?
- 2) How did they make sense of these experiences and how did this relate to their sense of wellbeing?
- 3) How does the relationship between wellbeing, meaning, and symptoms of psychosis evolve over time?

## **2. Method**

### **2.1 Aims**

To provide participants, living in North Wales in the United Kingdom, the opportunity to describe their experiences during the first year of the Covid-19 pandemic, March 2020 to February 2021.

To conduct a narrative analysis to describe participants' experience and to describe how they perceived their wellbeing as the pandemic progressed.

To analyse each narrative to identify themes of wellbeing change as the pandemic progressed.

### **2.2 Procedure**

#### **2.2.1 Recruitment**

Participants were recruited through an early intervention for psychosis service (EIPS) operating in North Wales, catering for a mix of rural and urban communities. EIPS staff were informed about the nature of the study with participant information sheets, in both English and Welsh, accessible to anyone interested in taking part. The EIPS provides a service for anyone who has had their first episode of psychosis in the last three years. Anyone using the service, able to provide informed consent to take part, and happy to be interviewed through the medium of English was eligible to be recruited. Given social distancing requirements, it was expected that the interviews would be carried out remotely. However, this was not a necessity as the researcher was prepared to meet participants face to face, using personal protective equipment, if required. Seven service users expressed an interest in the study and five, three men and two women, were subsequently contactable and provided informed consent to be interviewed.

#### **2.2.2 Interviews**

A key aim of the research was to understand how the participants' experience of the pandemic unfolded over time (see reflexive statement 2.4.1). Therefore, an interview structure was required that allowed participants to describe their journey as it appeared to them whilst at the

same time proving sufficient detail to allow for a fine-grained understanding of their experiences. Biographic narrative interviews were conducted in two parts (Wengraf, 2001), in the first part participants were asked a single narrative inducing question.

*“I would like you to tell me about your experience of the Covid-19 pandemic from the time just before you became aware of Covid-19, until now. I would like you to focus on specific events, situations, and occurrences that demonstrate how life has changed for you over this time.”*

In the second part of the interview, participants were asked further narrative inducing questions relating to the content brought up during part one. These questions were asked in the order the content was brought up in the first interview to preserve the structure of the original account (Wengraf, 2001). The researcher chose the follow-up questions based on the content most relevant to the overall aims of the project. These questions tended to focus on relationships, experiences of relative distress or increased wellbeing, and any unusual experiences.

Interviews were conducted in February 2021 and lasted between 75 minutes and 90 minutes, with a mean of 85 minutes. All interviews were conducted remotely using the telephone or video conferencing software, and were audio recorded.

## **2.3 Ethical Approval**

Ethical approval for this research was provided by the Bangor University School of Psychology and the UK Health Research Authority, south west Frenchay ethics committee.

## **2.4 Analysis**

### **2.4.1 Reflexive Statement**

As a novice researcher I was heavily influenced by discussions with the other two members of the research team, both experienced clinical psychologists working in the field of psychosis. From these discussions I became interested in the concept of psychosis as an experience of diverging and converging reality with the surrounding social milieu over time. The other researchers and I were aware of how our own experience of reality was being skewed by the pandemic, particularly the social uncertainty grounded in the risks of coming into close contact with others and novel rules of social interaction grounded in physical distancing and use of



video mediated interactions. I was interested in the impact of the shifting social world of the global pandemic on the experience of diverging and converging reality for people with psychosis, writing in my initial research protocol *'If psychosis is to be understood as stretches, and tears, in the psychological fabric that connects people to those around them, what happens when the entire psychological fabric of society starts to shift?'*. Also, given the increased focus on wellbeing generally during the pandemic it seemed that there was a risk that the suffering of minority groups would be subsumed within the suffering of the whole. People with psychosis are a disadvantaged and stigmatised group, it was important to me to provide an opportunity for their experiences of this turbulent point in our history to be told and heard. From this point onwards the notion that someone reading the final paper would be able to get a sense of the participants' experience as it unfolded before them took hold, influencing my subsequent methodological and analytical choices.

#### **2.4.2 Analytic Process**

Narratives were chosen as a vehicle for both the interview and the analysis for two reasons. Firstly, from a naturalistic epistemology, narratives are descriptions of specific experiences that can be located in time (Elliott, 2005). Therefore, focusing on participants' narratives allowed for the presentation, and comparison, of their experiences at fixed time points related to the pandemic. Secondly, the wellbeing focused approach adopted by the research team was primarily an attempt to understand how the participants saw themselves and their relationship to the world around them, as this world changed. This approach resonated with the ontological position taken by narrative analysis in that the self is a dynamic entity constructed and reconstructed in relation to the changing environment and social conditions (Esin, 2011). By elucidating the narrative structure that gives coherence to the experiences storytellers choose to foreground, narrative analysis reveals the patterns of self in which each storyteller is invested. Therefore, a narrative approach was chosen as the method of analysis most suited to the aims of the project, to describe change over time from the point of view of the participant.

From post interview and throughout the analytic process, a reflexive journal was used to record the overall gestalt of each participant's account as it appeared to the researcher. This record was based on theories of narrative structure and narrative communication (Fraser, 2004; Wengraf, 2001) and enabled the researcher to retain a sense of their subjective influence on the later interpretive elements of the analysis (see appendix 3)

In the first stage of the analysis the account provided by each participant was broken down into a series of 10 (+/-2) discrete events or periods of time known as a biographical data chronology (Wengraf, 2001). This number of data points was chosen to maximise sensitivity to the participants' experiential unfolding over time whilst providing a manageable, yet fine grained, level of detail. Discrete events included experiences such as the first shift back at work or a specific conversation recalled by the participant. Discrete periods of time were episodes, presented as such, by the participants, for example a period during which someone came to stay, or a period of distress (see appendix 4 and 5).

The second stage of the analysis was based upon the biographical data analysis approach outlined by Wengraf (2001). For each data point a series of hypotheses were generated about how the participant may have interpreted the experience. Each interpretive hypothesis was used to generate one or more predictive hypotheses, about what might happen next if the interpretive hypothesis were true, to be supported or refuted by subsequent data points (see appendix 6). Hypothesis generation was theoretically driven to focus the analysis on possible ways the participant may have interpreted their experiences from a wellbeing perspective. Wellbeing was defined by four characteristics which are loosely based on the factor model proposed by Ryff (1989) (see table 1)

<b>Wellbeing Characteristic</b>	<b>Description</b>
<b>Connection to others</b>	Building and maintaining relationships with others
<b>Self-esteem and Mastery</b>	Efficacy over emotional states through self-acceptance and environmental mastery
<b>Autonomy</b>	Opportunity and confidence to act on personal decisions and values
<b>Sense of Purpose / Growth</b>	A sense of meaning, direction, and growth

Table 1 – four aspects of wellbeing (Ryff, 1989)

As the researcher proceeded through the analysis they asked, 'how could this experience have contributed to this person's sense of wellbeing, and if so, what possible attributions were they making?' This process clarified the pandemic related contexts the participants had lived

through, along with the possibilities of wellbeing related meanings, both those chosen and those rejected, inherent within the contexts (see appendix 6).

In the third stage of analysis the hypothesised interpretations that appeared to be well supported in the narrative were woven together to provide a narrative summary of shifting appraisals over time. This final step was interpretive as researcher judgement was required to decide which of the more equivocal interpretations should be retained, and how the retained interpretations related to each other. The guiding principle at this stage was holistic coherence; creating a structured narrative which was internally coherent and made sense in relation to the unfolding experience of the participant, the stages of the pandemic, and resonated with the gestalt of the verbatim account (see appendix 7).

In the final stage of the analysis the final narrative summaries were broken down into five stages: ‘pre-pandemic’, ‘into lockdown’, ‘lifting of lockdown’, ‘the imposition and lifting of local lockdowns’, and ‘Christmas and full UK lockdown’. Experiences of wellbeing in each of these stages were compared across participants to explore similarities and differences at each stage (see appendix 7). Secondly, the narrative summaries were analysed individually to identify themes of change over time. Turning points, at which there were changes in the way that the participant was interpreting themselves and their environment, were identified (Wengraf, 2001). Turning points were grouped thematically to elucidate the process of change. For example, if the participant seemed to be reluctantly aligning their attributions to the world around them the change would have been labelled, for example, ‘compliance’, or if they were attempting to find common ground they would have been labelled, for example ‘finding consensus’ (see appendix 8).

### **2.4.3 Credibility and Trustworthiness**

Credibility and trustworthiness in qualitative research are maintained by providing an account that remains true to the data provided by participants and which resonates with readers. All participants were sent a copy of the narrative summary produced from their interviews, and feedback elicited. Where possible participants were encouraged to give feedback over the phone to allow a detailed discussion about the results, alternatively participants fed back via e-mail. All five participants provided feedback. Three out of the five provided a straightforward confirmation that they were happy with the way their narrative summary was presented.

Charlotte<sup>1</sup> (see 3.1) said that she found reading the narrative summary validated her experiences, especially as her name had been replaced with a pseudonym, foregrounding the objective credibility of her account. *'It's easy to for me to stick the pain and suffering to the back of my head, reading through it reminded me that what happened was relevant and important'*. Deiniol reflected that the pandemic had disorientated him, and that he could not remember what he had said during the interview, but that he recognised the pattern of experience, that came through in the summary, of his uncertainty and discomfort easing during periods of lockdown and increasing again as restrictions were eased.

Regular meetings were held between the researchers throughout the analysis process. To support thematic development, emerging themes were critically appraised by all three researchers and consensus reached on how to interpret and describe the common experiences and processes of change across the five accounts.

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<sup>1</sup> All participants names are pseudonyms used to protect their identity

### **3. Results**

#### **3.1 Participants**

Descriptions of the five participants and their experiences during the pandemic are presented in the present tense in order to foreground their unfolding experience.

Claire, in her early thirties, is a single mother and full-time carer, who has a background of childhood trauma, and spent some of her childhood in care. Charlotte, in her mid-thirties, lives with her husband, and young son, and works part time in a local café. Charlotte previously worked full time and has struggled to adjust to a more limited lifestyle since experiencing post-partum psychosis. George is a single, full-time student, in his early twenties, who lives with one housemate. George started to struggle with his mental health after he left home and is very critical of how he acted in the past. Carl is in his mid-twenties, is single, and living in supported housing. Carl grew up in foster care and has only recently left psychiatric hospital. Deiniol is single, in his early thirties, and living alone, his only regular social contact is with his mum and mental health services. Deiniol has recently recovered from a period of psychosis.

#### **3.2 Second Reflexive Statement**

After the transcription of the interviews, I became conscious of a perceived, or hoped for, developmental trajectory reflected in the structure of the narrative provided by each participant. For example, George seemed to be conveying a story of recovery, whereas Carl and Deiniol seemed to be conveying a story of development thwarted, or paused, due to the convulsions of the pandemic, and both Claire and Charlotte seemed to be expressing their attempts to maintain stable development in response to these convulsions. This resonated with my own experience of the pandemic and the way it had brought into focus my developmental goals as an individual, a father, a husband, and a trainee clinical psychologist. I reflected that development is a key aspect of recovery from severe mental illness (SMI), given that SMI often represents a period of social disconnection, stigmatisation, and therefore stalled development. Therefore, I was keen that the narrative summaries also represented each participant's sense of their own development as well as their experience of a reality converging and diverging with those around them.

### **3.3 Narrative Summaries**

The narrative summaries for each participant, along with their wellbeing related themes for each stage of the pandemic, are represented below in figure 1. The participants' experiences, and themes, are then described in more detail in the tables 2-7.

**Figure 1** Time line of participants' experiences as the pandemic progressed

	FEBRUARY 20	MARCH 20	APRIL 20	MAY 20	JUNE 20	JULY 20	AUGUST 20	SEPTEMBER 20	OCTOBER 20	NOVEMBER 20	DECEMBER 20	JANUARY 21	FEBRUARY 21	
Pandemic events		WHO labels C-19 as a pandemic  Schools close  Full lockdown begins		UK passes peak of infections	First easing of lockdown	Non-essential shops open  Schools reopen	Travel restrictions lifted  Outside attractions reopen  Limited meeting allowed indoors	Restaurants etc fully open	First local lockdown in Wales	Wales-wide lockdown starts	Wales-wide lockdown ends  Vaccine roll-out starts	Schools do not reopen after Christmas	Schools reopen in Wales & PM announces roadmap for easing lockdown	
Time period	Pre-pandemic  see Table 2		Into lockdown  see Table 3		Lifting of lockdown  see Table 4			Imposition and then lifting of local lockdowns  see Table 5			Christmas and full, national lockdown  see Table 6			
Claire themes	< Isolated yet connected – Mastery over uncertainty >				< Struggling to maintain mastery over uncertainty – Maintaining routine >			< Struggling with increasing uncertainty >			< Finding solutions >			
experiences	Advised to prepare  Takes son out of school, partner comes to stay  Support from services reduce, worries about health and food security  Happy memories spending time as a family				Partner returns home and son starts school  Self harm increases  Socially distanced walks with friends  Hypo-manic episodes			Son back at school full time  Pressure to socialise and get things sorted  Period of low mood			Acute sense of fear  Believes the government is watching and controlling her and that she has the cure for covid in her blood  Decides to ask for school place for son			
Charlotte themes	< Isolated yet connected – Mastery over uncertainty >		< Overwhelmed, paranoid >		< Reaching out for help >		< Overwhelmed, paranoid, and lacking purpose >			< Facing up to the problem >			< Thwarted connections and autonomy >	
experiences	Supposed to go on holiday but stays at home		Work closes, local environment becomes crowded  Hears neighbours judging, criticising and laughing at her  Stops going into back garden  Starts medication		Shouted at and laughed at whilst out walking		Cuts down medication  Sent home from work  MHT visit  Anxious and suicidal			Support to go out independently  Hypnotherapy  Spending time in garden despite discomfort  Attempts to return to work but can't manage it			Trying to get out once a day with husband and son	
George themes	< Overwhelmed and distracted >		< Finding space for self-development >		< Attacking new challenges >			< Regaining mastery >			< Hope >			
experiences	Two trips away with university  Feels others are accessing his thoughts  Feels weak and 'like a social outcast'		Home from university, released from social pressures  Starts running  Angry with self and anxious		Running continues  Feeling better but aware of aggression towards others  Expedition with friends. Angry with friends and self  Starts work with bricklayer			Back to university and unsure of ability to cope  Lectures online  Running continues  Can successfully avoid people he thinks will try to undermine him			Relief at quiet Christmas  Is able to cope with bumping into people that he tries to avoid  Has flashbacks of anxiety but suppresses it			
Carl themes	< Overwhelmed and distracted >		< Overwhelmed, paranoid >		< Overwhelmed, paranoid and lacking purpose >			< Struggling with increasing uncertainty >			< Thwarted connections and autonomy >			
experiences	Comes out of hospital - and moves into shared house		Only allowed to leave the house for one hour a day  No face to face support. Feels ignored  Stops medication		Struggling to make friends away from drug use  Starts visiting his mum's house  Finds bike riding a release but has to fight to control anxious thoughts  Develops a friendship with an old acquaintance			Holiday with sister is cancelled  Mum stops him going round due to fear of fine  Acquaintance loses accommodation and moves away			Misses his family opening Christmas presents. Rules prevent him from staying overnight  Obsessions and compulsions increase  Notices affects of reduced support from MHS			
Deiniol themes	< Overwhelmed and distracted >		< Isolated yet connected – Mastery over uncertainty >		< Struggling to maintain mastery over uncertainty /maintaining isolation >			< Regaining mastery >			< Hope >			
experiences	Psychological treatment ending  Worried about return to a less isolated 'normal' life and relapse		Job interview and walking group cancelled  Realises that isolation is now expected of him  Stops worrying about relapse  Mum starts shopping for him		Needs to go out but worried about forgetting to follow social distancing rules  Spends time learning rules  After going to the dentist opts to maintain isolation. Believes he will be judged for leaving the house unnecessarily			Family gathering outside for niece's birthday  Conversations with others focus on the pandemic and not on recovery  Experiences reduced pressure to change			Christmas is quiet with less pressure to conform than usual  Mum has vaccine  Treatment groups postponed  'It seems like the pandemic will go on for some time'			

Description	Quotes	Themes
<b>Claire and Charlotte</b> are encouraged by their respective partners to isolate and prepare. A period of trust and emotional closeness to her partner begins for Claire that buffers her from the uncertainty of the developing pandemic. Charlotte finds relief from the emotional turmoil of being around others.	<i>'I trust my boyfriend, I trust his opinion, and I kind of felt like it was good to be prepared. I have a lot of anxiety and I think it was really good to have somewhere to kind of direct it'</i> Claire (3) <sup>2</sup>	Isolated yet connected  Mastery over uncertainty
<b>George, Carl and Deiniol</b> are all focusing on significant personal challenges and are relatively unaware and unconcerned by the approaching upheaval. George is feeling persecuted by other students at the university and is having experiences of thoughts being put into his head. Carl has just left psychiatric care and is looking forward, with some trepidation, to trying to 'sort his head out'. Deiniol is attempting the next stage of his recovery from psychosis, including arranging a job interview, and fears relapse.	<i>'I had some symptoms at that point (and) because I had other things on my mind... I was still in my thoughts not thinking about whether this pandemic was going to affect me at all, in a weird kind of way... I just sort of let it take place.'</i> Deiniol (5)	Overwhelmed and distracted

**Table 2** Pre-pandemic

<sup>2</sup> Numbers refer to transcription section, see appendix 2



Description	Quotes	Themes
The relative isolation of lockdown buffers both <b>Claire</b> and <b>Deiniol</b> from the difficulties and uncertainty they experience in their interactions with the outside world. Yet both find increased connection amongst this isolation as they see others struggling with their mental health as they do. The isolation brings Claire closer to her son and partner, who has moved in for the lockdown.	<i>'We got to spend more time together and there wasn't the stress of everyday life, so even though we had this big picture stuff in the background I felt less anxious I wasn't getting stressed about having to socialise on bad days'</i> Claire (12)	Isolated yet connected  Mastery over uncertainty
<b>Carl</b> also experiences isolation living in a small room in a busy supported housing complex, not able to see family and friends or have face to face contact with support staff. However, due to lockdown restrictions he is only able to leave for one hour a day. This means he is overwhelmed by the lack of space from other residents; he finds his thoughts race and he fears relapse.  Lockdown brings an influx of people into <b>Charlotte's</b> local environment. For example, people are constantly in their back gardens. She feels under constant scrutiny and hears others criticising her and laughing at her. Charlottes' husband encourages her to interpret this as psychosis. She feels both disconnection from others and stifled.	<i>'I couldn't go out... you can't... there's only so much you can do like... I felt dead wired all the time. That's what it's like when you go dead manic'</i> Carl (116)  <i>'I told my husband, but he was like "oh it's psychosis" but it's not always psychosis... I then started to have some psychotic episodes which eventually gave me enough fear not to go and exercise in my gym cos I felt guilty'</i> Charlotte (7, 8)	Overwhelmed, paranoid
The isolation of lockdown is a welcome opportunity for <b>George</b> to get distance and space from others and, with it, an increased sense of autonomy that enables an improvement in self-esteem.	<i>'Lockdown was extremely liberating for me. I didn't need to see anybody for starters...the exercise really helped, I started doing a lot of running... I got quite a bit better'</i> George (8)	Finding space for self-development
<b>Charlotte</b> decides to interpret some of her challenging experiences as psychosis. This leads to a prescription for anti-psychotic medication and increases her sense of connection to her family.	<i>'He (husband) mentioned about drugs... I was kind of with him, more for his sake than my sake, because he's had to go through it with me... when it's someone you love who goes through it with you, it's tough for them.'</i> Charlotte (36)	Reaching out for help

**Table 3** Into lockdown

Description	Quotes	Themes
<p>Stability and comfort give way to uncertainty and distress for <b>Claire</b> and <b>Deiniol</b> as social contact restrictions are eased. Claire's partner returns home, her son starts school and her self-harm increases. The proliferation of rules around social interaction makes the prospect of engaging with others more daunting than ever for Deiniol.</p> <p>Claire responds by using social distancing rules to negotiate a routine of spending time with her friends in a way that enables her to feel unusually secure in social situations. Deiniol's forays into the outside world are much less successful and he opts to remain in relative isolation.</p>	<p><i>'I found that much easier having like one-on-one time with my friends rather than meeting in a group... there was less like social anxiety' Claire (14).</i></p> <p><i>'there's still the sort of feeling in the air (that) there has to be a very serious reason for you to have to be out at all... it's much easier being at home and thinking everyone is in the same situation' Deiniol (114)</i></p>	Struggling to maintain mastery over uncertainty
<p>The easing of social contact restrictions does little to alleviate <b>Charlotte's</b> and <b>Carl's</b> on-going struggles with their symptoms and to find connection with others. Charlotte is sent home from the café where she works as infection control measures, such as personalised table service, have disrupted her ability to control her proximity to customers and her anxiety whilst working. Carl is free to leave his accommodation for longer periods and meets with his mum regularly to try and build a 'bond' with her. However, he is unable to get the peace of mind he is searching for.</p>	<p><i>'that kind of sent me to pieces cos... my work was my way of communicating with outside world. My friends were there, they're more like family, and I'd kind of lost them' Charlotte (10)</i></p>	Overwhelmed, paranoid, and lacking purpose
<p><b>George</b> continues to develop his self-esteem, achieving objectives such as going on an expedition with his friends and finding work. George reconnects with others with a sense of self-assuredness, however at times he feels like he is over-compensating.</p>	<p><i>'I felt like it was a real opportunity to kind of improve myself... I organised like a kayak trip down the river ***** for like three days... I remember being really angry and pissed off with my mates because they were just so useless... I was making progress and they weren't and that was annoying me. In reality I was just being a dickhead' George (33)</i></p>	Attacking new challenges

**Table 4**    **Lifting of lockdown**

Description	Quotes	Themes
Rules around social contact are changed with little notice, bringing with it a lack of control that is reminiscent of <b>Claire's</b> childhood in care. With her son back at school she feels greater pressure to meet up with others. <b>Carl's</b> mum asks him to stop going to her house as she is worried about prosecution and his plans for a holiday with his sister are cancelled, disrupting his sense of routine and connection to others.	<i>'that (the imposition of lockdown) really messed my head because I had all my bag packed .... I had everything organised, I'd worked out my budget.... I had all my money ready, I had all the things planned up on a piece of paper what I was gonna do with my sister'</i> Carl (117)	Struggling with increasing uncertainty
<b>Charlotte</b> has reached a point of complete hopelessness and disconnection and is too anxious to leave the house on her own. She reaches out for support from local mental health services and a hypnotherapist. With support Charlotte begins to expose herself to avoided situations, for example being in her back garden, and experiences empowerment from the realisation that at times, although she feels threatened, she is safe.	<i>'I could see some things were just background noise that I was finding threatening... yeah it wasn't pleasant, but it did help... just accepting it for what it is even if it was real, even if it's psychosis... just be there in the moment and know that I'm still safe.'</i> Charlotte (60)	Facing-up to the problem
The reimposition of social distancing rules enables <b>George</b> and <b>Deiniol</b> to regain a sense of mastery over themselves and their environments. George is back at university but distance learning means he can avoid others that he finds threatening. He focuses on his fitness and university work to maintain his self-esteem. Deiniol, again, finds sense of purpose as the expectations of society seem to align with what he finds most comfortable, keeping himself isolated.	<i>'The second lockdown seemed to make me think; this is how it's gonna be now for a very long time. There's less pressure on me to do things that don't fit me and this competition in society of being a certain person ... there's a lot less pressure now on people.'</i> Deiniol (29)	Regaining mastery

**Table 5** Imposition and then lifting of local lockdowns

Description	Quotes	Themes
The hastily introduced UK wide lockdown and school closures leave <b>Claire</b> feeling out of control and in search of certainty and meaning. She struggles to sleep and has a series of psychotic experiences believing the government is watching her and trying to control her, and that she has a cure for Covid in her blood. Claire recognises she is struggling and requests extra support for her son. Despite regaining some sense of control, Claire feels disconnected and purposeless.	<p><i>'I became convinced that there was something in my blood, that I had the cure, the cure for covid'</i> Claire (24)</p> <p><i>'At the moment I have noticed that I'm feeling more lonely and kind of useless like I'm not contributing'</i> Claire (35)</p>	Finding solutions yet disconnected
<b>Charlotte</b> and <b>Carl</b> also experience disconnection and purposelessness in a world devoid of social contact. Carl buys all his family Christmas presents for the first time in his life but misses them being opened as he is unable to stay with his family overnight. Charlotte has attempted to go back to work but decides she cannot manage. The lack of opportunity to meet with others leaves her experiencing a lack of independence.	<i>'So I've kind of lost that what I used to try and do which was really important to give me – that kind of independence feel, even though it's not real independence, which I'm well aware of, but it had the ability to make me feel good about myself'</i> Charlotte (13)	Thwarted connection and autonomy
Conversely <b>Deiniol</b> and <b>George</b> both feel hopeful about their future. A Christmas without large gathering provides George time to further buttress his sense of autonomy and self-esteem. At university he finds that he less concerned about what others think of him. For Deiniol the on-going postponement of treatment and the rise in new variants of Covid-19 make it seem like any expectation of change is some time off. However, this is tinged with a sense of uncertainty about how he will manage when this day comes.	<p><i>'There was a guy there (in the library) that I knew who was one of this kind of people that I really didn't want to see... and I just walked to my desk, did my work, and left and didn't give it a second thought.'</i> George (17)</p> <p><i>'The pandemic has definitely delayed a lot of getting used to things I had difficulties with... but I will have to at some point but I don't know when.'</i> Deiniol (37)</p>	Hope

**Table 6** Christmas and full, national lockdown

### **3.3.1 Summary of participants' experiences**

The participants gave individually distinct accounts with each experiencing periods of deterioration in their wellbeing and mental health, and periods of improvement, but at different times. Only Claire and Carl suggested that the pandemic had had an overall deleterious effect on their mental health whereas both George and Charlotte experienced some recovery. For Deiniol the lockdowns and disruptions caused by the pandemic were an opportunity to take a break from a fearful 'return to normal life' but left him feeling relatively stuck. The start of the pandemic represented a turning point in wellbeing for each of the five participants. Deiniol and Claire experienced further turning points which corresponded directly with changes in the course of the pandemic, such as in infection risk or rule changes, whereas the turning points for George and Charlotte were related to specific personal events, such as returning to work or university. Carl's narrative was one of being consistently thwarted in his attempts to establish a sense of stability and wellbeing and did not demonstrate any further turning points.

Space and access to social support were key determinants of wellbeing and mental health. Those who were able to find space away from others found imposition of lockdowns easier and restorative whereas those who did not experienced deterioration in both wellbeing and mental health. However, it is important to note that this was not just about physical space but also psychological space, as Charlotte had access to a private house and garden but found her relative privacy reduced when all her neighbours were spending their time at home. Carl found the pandemic the most overwhelming and detrimental to his wellbeing. Carl was the only participant who did not have a trusted friend, partner, or family member who was consistently available irrespective of social distancing rules. All participants experienced some difficulty in navigating the repeated changes to the way that social life was organised in response to the pandemic. Finally two of the participants, Claire and

### **3.4 Themes of change over time**

Salient in all five narratives is a sense of threat and uncertainty associated with connecting to others. This was linked to a tension between this aspect of wellbeing and other aspects of wellbeing that can be broadly labelled as a coherent sense of self. For example, difficulties maintaining a sense of autonomy through being judged, undermined, or criticised.

*I was seeing people and kind of just putting my head down and not being able to make eye contact.... and just saying, you know what, just do what you want to me but just don't fucking hurt me too badly. George, pre-pandemic<sup>3</sup>, (37)*

Struggling to make sense of their own emotional experience.

*I'm just trying to deal with these compulsions and obsessions in my head like and I'm trying to do stuff and people are distracting me... I'm like oh god these are a nice people but I'm going to flip out. Carl, into lockdown, (144)*

Struggling with a sense of self-esteem and acceptance.

*I was just like looking at all the pictures (on social media) and felt that I should be doing more. I should be doing the same as other people, 'why aren't I making the most of this time, why aren't I enjoying home schooling?' Feeling really down about myself, I felt like other people were coping better than me. Claire, into lockdown (121)*

The themes of change elucidated how participants experienced, and engaged with, this interplay between connecting with others and maintaining a coherent sense of self as the pandemic evolved.

### **3.4.1 Converging Reality**

The risk of illness and mandating of social distance had an impact on society generally. As others became more wary of social contact, and more vulnerable to the impacts of stress and isolation, the participants' own challenges with self-esteem and self-acceptance were normalised and they found the opportunity to feel more connected and in touch with those around them.

*Conversations with people, friends, were really kind of talking about their anxiety about the pandemic and about change... I can remember just sitting there and listening and*

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<sup>3</sup> Pandemic stage – see figure 1, tables 2-7

*thinking... 'they're like really feeling the same kind of anxiety as me'.* Claire, into lockdown, (110)

### **3.4.2 An Opportunity for Retreat and Increased Control**

These altered expectations around engagement with others allowed participants the opportunity to put their struggles with connecting to others to one side, and find a sense of purpose in their relative isolation.

*It just puts it into perspective what my expectations are for myself... and what other people's expectations of me are as well.. because they'd put everyone else in the same situation. I think expectations have changed at the moment.* Deiniol, into lockdown (77)

Social distancing also allowed participants greater control over how they interacted with others creating opportunities to reduce fear of criticism and self-doubt whilst connecting with others. For example, Claire's description of reduced levels of social anxiety at times when social distancing rules were most stringent, and in George's description of the benefits of a face mask:

*"a mask kind of just covers that part (of my face) and I kind of have a far more effective conversation without..... overthinking and stuff".* George, lifting of lockdown (147)

### **3.4.3 Reduced Control and Enforced Retreat**

Conversely, restrictions on movement disrupted participants' tried and tested control strategies and forced them to retreat from social connection. For Charlotte, the first three stages of the pandemic seemed to represent a slow retreat as she realised that the strategies that she had used to find space, autonomy, and manage her anxiety were no longer available to her.

*(previously) if I was serving the builders or whatever [at work in a café] ... I could take five or someone (else) could take over (but) because of the new way of service you serve them all the way through and you have to stand by their table to make sure they're ok and.. just the thought of it I was shaking.* Charlotte, lifting of lockdown (50)

This process continued until she reached the point that she felt completely disconnected.

*I couldn't do it I was shaking so (much) they sent me home and then that kind of sent me to pieces. My work was my way of communicating with the outside world my friends were there, they were they're more like family, and I'd kind of lost them.* Charlotte, lifting of lockdown, (10)

Likewise, Carl's experience of living in shared accommodation with restrictions on how frequently he could leave, led him to break rules which contributed to difficulties in engaging with support.

*I snuck to my mate's for one night cos I couldn't cope in the building. As soon as I got back the staff told me I had to isolate in my room for a whole week like... and I was really really stressed out.* Carl, lockdown, (134)

#### **3.4.4 Successful re-emergence, relinquishing control**

George and Charlotte, who experienced a process of recovery, appeared to respond to periods of retreat in a way that helped them to re-emerge with a more robust self-coherence when connecting with others.

Their respective periods of retreat appear to have a productive quality. For George this is tied up in the attribution that he makes of himself as being weak and allowing others to influence and control him, with the start of the pandemic an opportunity to address this, often aggressively, thus helping to develop his sense of self-esteem.

*I ran 10 miles when I first got home... I just remember hurting so badly and being like 6 miles into the run and just being like 'you've got to carry on there's no way that you're stopping', absolutely like punishing my body... it was quite rewarding but it was a way to get my own back on myself.* George, into lockdown (105)

The idea that he was subsequently stronger, both mentally and physically, meant that George felt that he could stand up to those that might seek to undermine him.

*I could feel them fucking beady eyes looking in the back of my of head....so it did bring it (self-doubt and paranoia) back again but I was kind of in a lot more of a strong, more positive,*



*mindset and I was able to shut it down, and to ignore, and to not really pay attention to it.* George, imposition and lifting of local lockdowns (16)

Charlotte reached out for help from therapists and services. This appeared to trigger an attitudinal shift whereby she relinquished some control over her interactions by, firstly, trusting the opinions of those supporting her, and secondly, trying to tolerate some discomfort.

*The hypnotherapy lady, she actually helped quite a lot, she explained how it's actually vital and it's part of my self-care routine and if anyone did say anything, what kind of person would say that, and do you want to live your life by that? To the point that I could go out there, and do a little bit, and still obviously have everything going on, and sometimes hear people saying stuff, or laughing, but being able to say 'well this is my right this is what I'm allowed to do' Charlotte, imposition and lifting of local lockdowns (60)*

This move towards relinquishing control appears to be central to Charlotte's process of recovery.

*that kind of became my way.... just accepting it for what it is even if it was real, even if it's psychosis, just be there in the moment and know that I'm still safe, which is the big one for me, no matter what happens I am safe.* Charlotte, imposition and lifting of local lockdowns (60)

For George, his quest for self-development seemed to focus on increasing his mastery over his own internal experience in response to other's attempts to undermine him. However, a parallel process also took place whereby he recognised he did not always need to defend himself.

*That was the point where I was realising like I need to .... stop maybe attacking people, and that, and start being a bit nicer because not everyone is trying to fuck with you.* George, lifting of lockdown (33)

This helped him to maintain a sense of self coherence even when he was not feeling as strong, for example in the following quote where George explained how he maintained eye contact and civility whilst in the library, despite a sense of vulnerability and an urge to withdraw.

*I was in not good state.... she was basically asking me to go over and help her do this work... I was kind of looking at her and just really trying to make sure that I wasn't going to put my head down or... do anything weird.* George, imposition and lifting of local lockdowns (37)

### **3.4.5 Challenging re-emergence, maintaining control**

For the other three participants periods of retreat do not allow for developed self-coherence. Deiniol opted not to re-emerge as his fears of how he will be judged by others persist.

*the pandemic has sort of reassured that that I won't give me a situation to be... psychotic anymore because I don't go out, I don't see anyone, ..... that's how it's eased things, a sort of false reassurance in a way.* Deiniol, imposition and lifting of local lockdowns (59)

Carl, who struggled to find space for retreat, also struggled to make progress, alluding to difficulties in finding peace with his internal experience.

*I've noticed my thoughts can be quite bad when I'm around people they trigger more when I'm around people and that, but then when I'm on my own for too long ..... it's like you think it's helping you being on your own but then it's not..... everything I do is a trigger.* Carl, lifting of lockdown (154)

In her account Claire talked about lessons she had taken from her experience of the pandemic. However, she seemed less able to use these in a way that helped her to re-emerge with sense of self coherence. Each change in stage of the pandemic brought with it a sense of crisis that she had to rebuild from.

*When the lockdown started to ease up it was like a big change again to get used to... yeah it was hard to get back in that routine, and my partner went home, and I actually really started struggling then. I had a big increase in how much I was self-harming, and it was difficult for a while.* Claire, lifting of lockdown (13)

Just as Charlotte and George's preparedness to relinquish control in their interactions with others appeared to play a role in their relative recovery, impulses to establish control, or fearing the consequences of losing it, seemed to play a role in difficulties experienced by the others.

For example, Carl places heavy emphasis on his inability to maintain control of his internal experiences.

*I've got to be really really in control before I go out, cos if I'm not in control before I go out, I don't enjoy my bike ride as much, I just don't enjoy it* Carl, lifting of lockdown (163)

The need for control as a barrier to recovery is most vividly apparent in the account given by Claire whereby her drive to maintain a sense of control over a highly uncertain external environment led her to a series of psychotic experiences.

*I became convinced of this (that she had a cure for Covid in her blood) really and it made me feel really good. I guess that my brain wanted... real life was a bit too much and I wanted a solution... but then again it did kind of turn into a bit of a nightmare because I then became convinced that the FBI, that a swat team, were gonna come and get me.* Claire, Christmas and full UK lockdown (26)

### **3.4.6 Meta Themes**

Two ‘meta themes’, meaning and struggle, were apparent across all the themes of change.

#### **Meaning**

As the pandemic unfolded, population level changes to emotional health, and social expectations, enabled participants to position themselves in respect to their environment in new ways that allowed for new opportunities for wellbeing. For example, finding justification and purpose in social isolation, or finding opportunities to relate to others experience of emotional distress. Likewise, participants were actively making sense of their subjective experience which affected the way that the relationships between different aspects of wellbeing, such as connection, autonomy and self-esteem, evolved over time. This is most vividly apparent in George’s interpretation of his thought disturbance in terms of his own weakness which, although detrimental to his self-esteem, instilled him with a sense of purpose, to improve himself, and eventually allowed for self-acceptance. The theme of relinquishing control is related to the development of a nuanced sense of self in which contradictory positions co-exist, for example weakness and strength in the case of George, and safety and threat in the case of Charlotte.

## **Struggle**

Apparent in all accounts, regardless of whether a participant experienced recovery or otherwise, is the ongoing process of struggle with adversities. This refers to the capacity of each person to pick themselves up from, invariably repeated, setbacks to try to find stability and make progress in a world that can seem very hostile. This remarkable resilience and persistence shown by each participant is manifest in the overall structure of each story, which detail periods of stabilisation, or development, punctuated by events that invoke doubt and uncertainty. This phenomenon, clearly visible here, is absent in the cross sectional and quantitative studies of psychosis.

*'My husband says that I am like rocky four, I just keep hitting'* comment by Charlotte in the follow-up interview.

## 4 Discussion

This study had two broad aims: to describe the experiences of people with psychosis during the Covid-19 pandemic, and to explore the relationship between the participants' context, their unusual experiences, and attributions of wellbeing.

The findings demonstrate that there was considerable variation in experiences of people with psychosis during the covid 19 pandemic. This supports current research outlining that people with pre-existing mental health conditions should not be considered a homogenous group when responding to their needs as the crisis recedes (L. Murphy et al., 2021). This study advances current understanding by demonstrating that the pandemic has not been a singular event but a series of changes in the way that the social world is organised, with a knock-on impact on the availability of mental health support, social activities, and social roles such as work and education. Coping with the churn that this seemed to create, navigating both the loss of these activities and re-entry into them, proved difficult for the participants. This is understandable given challenges people with psychosis have with psychological processes such as maintaining a sense of self (Lysaker & Lysaker, 2001; Connell et al., 2015), regulating emotions (Livingstone et al., 2009), and maintaining social contact (Mueser & Tarrier, 1998).

In this study the experience of social support was integral to people with psychosis' experience of the pandemic. All participants with consistent access to a trusted other, but not those without, were able to find periods of stability and overall wellbeing as the pandemic unfolded. This corroborates existing research demonstrating that access to social support plays an important role in the relationship between the onset of the pandemic, deteriorating mental health, and a sense of wellbeing (Asmundson et al., 2020; Gobbi et al., 2020; J. Ma et al., 2020; D. Murphy et al., 2020; O'Connor et al., 2021; Pinkham et al., 2020). As with Riblet (2020) the current analysis extends these conclusions by illustrating that social support is a nuanced concept which is related to physical and psychological space, experiences of connection to others, and autonomy.

As well as social support the theme of 'converging reality' pointed to the fact that some participants found a sense of connection to society more broadly as they recognised that their experiences were being shared by others. It is of interest that this was not a universal experience, with three of the five participants not mentioning this at all, given that the

universality of experience across society was a salient characteristic of the early stages of the pandemic. This perhaps reflects the challenges in maintaining a coherent sense of self reflected in the narratives of the participants. It is clear from these accounts that a closeness to others can bring its own challenges for those with psychosis and therefore it may be actively rejected or disregarded as people construct their narratives. The lack of reference to a commonality of experience may also relate to the theme of struggle. The struggle to maintain a sense of coherence and stability will undoubtedly require a high level of focus on the proximal environment leaving little space to reflect on what is happening in wider society.

In terms of the relationship between psychosis and wellbeing, an account emerged demonstrating a complex interplay of different aspects of wellbeing evolving over time and in response to an individual's experiences and environment. Integral to this interplay was the theme of '*struggle*' whereby participants worked tirelessly to maintain and enhance their wellbeing. Of particular interest is the struggle between connection to others and what is termed a coherent sense of self: autonomy, self-acceptance and self-esteem, and control over internal experiences such as thoughts and emotions. Difficulties with the experience of a coherent sense of self in psychosis have been discussed previously using the term the dialogical self (Lysaker & Lysaker, 2001; Connell et al., 2015), which relates to the challenges of integrating the various facets of experience and behaviour into a coherent whole. This study was not designed to explore poor self-coherence in detail but elucidated processes that people engage in to help themselves deal with the sense of threat associated with it (Connell et al., 2015).

First and foremost was the concept of control and relinquishing control. The behaviours and psychological processes that were included under the theme of control in this study were varied. It included those that are common in emotion and psychosis research such as trying to suppress or ignore particular emotional experiences (Livingstone et al., 2009) and maintaining distance from others (Mueser & Tarrier, 1998; Andersson et al., 2015). This study also described processes that are less well researched such the control of self-image as demonstrated by George and Charlotte. Relinquishing control, or acceptance, is a central process in third wave therapies particularly acceptance and commitment therapy (ACT) which has an emerging evidence base in psychosis (Wakefield et al., 2018). What is apparent in these narratives is the role that acceptance plays in helping people with psychosis integrate opposing ideas about themselves, weakness and strength or safety and threat, which supports self-coherence and

connection to others. The role of ACT treatments in establishing self-coherence in psychosis is an area of potential future research.

Retreat and subsequent re-emergence also emerged as two themes of change. The theme of re-emergence is associated with both the recovery movement (Leamy, Bird, et al., 2011; Law & Morrison, 2014), and the concept of post traumatic growth (Joseph & Linley, 2005; Park, 2010, 2013). It relates to finding meaning in distress, and illness, and the transformation into a more stable, contented, and purposeful life. In exploring re-emergence as the participants experienced it, this study foregrounded the fraught nature of this process and the on-going struggle of those with psychosis to engage with it. Regardless of whether it was chosen, or whether there was no choice but to engage with the struggle of day-to-day existence, re-emergence posed risks to the coherence of self and subsequent distress. Emphasising these challenges builds on research highlighting the importance of retreat in helping people with psychosis to maintain their wellbeing (Corin & Lauzon, 1992; Andersson et al., 2015). The struggle with re-emergence and the utility of retreat also draws attention to the non-linear nature of recovery from psychosis and serious mental illness (Leamy, Bird, et al., 2011) and is an important clinical outcome of this study.

Finally, the utility of each of these movements, to retreat or emerge, control or integrate, was influenced by the way that participants made sense of the world, their idea of the relationships among their experiences, subjective or objective. This highlights the importance of using therapeutic approaches that help service users make sense of their experience in a way that is both helpful and valid for them (Moritz et al., 2018) rather than considering treatment as primarily the amelioration of deficits.

#### **4.1 Study limitations and recommendations for future research**

This study was a narrative analysis with a very specific remit to explore change in wellbeing related appraisals over the course of the Covid-19 pandemic. Consequently, this involved a relatively deductive approach to the analysing of the data, it prioritised the order of the events as they occurred in time rather than the weight given to them by the participant, and assumed a certain structure and character of wellbeing. These choices were deemed necessary in order to provide an understanding of the participants' experiences relative to events external to them, and to give the narrative summaries a coherence that made them comparable to each other, and

accessible. These choices meant that some of the information the participants provided on their subjective experience of the pandemic was demoted to make way for a sense of cognitive and emotional change over time. This attempt to identify the coherence of the participants' narratives across time had the effect of neglecting some of the lack of structure and incoherence that some of the participants experienced at some of the times during the pandemic. However, it is important to note that a great deal of effort was put into retaining the overall gestalt of the participants' accounts in the narrative summaries, with open feedback from all five participants confirming their accuracy.

This was a small study which aimed to explore the variation in experiences of people with psychosis during the covid-19 pandemic. The small and varied sample meant that it was a challenge to draw out commonalities amongst the narratives provided and meant that some of the themes, for example successful re-emergence, were only experienced by two participants. Consequently, it was not possible to provide a comprehensive exploration of the themes identified from the perspective of people with psychosis. Further research is warranted. This research could focus on one specific characteristic of experience of the pandemic, for example relative recovery or relative deterioration of mental health, to continue and expand on the analysis provided here.



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## **Chapter 3 – Contributions to Theory and Clinical Practice**

## **Contributions to Theory and Clinical Practice**

The two studies presented in this thesis provide an interesting view on the confluence between research, particularly quantitative methods, and the day-to-day experiences of service users and clinicians.

One of the key findings from the empirical paper was the active role that people with psychosis play in maintaining self-acceptance, autonomy, and self-esteem in their relations with others. For the participants in the study these characteristics of wellbeing were not easily attained requiring consistent struggle. This struggle was physical, psychological, and cognitive. The physical struggle focused on finding space away from others. The psychological struggle focused on managing and mitigating the distress that could be associated with connecting to others. The cognitive struggle was finding ways of making sense of their experiences that allowed for wellbeing and hope.

This is further evidence that when people with psychosis are given time and space to talk about how they make sense of, and respond to, their experiences they appear as co-creators shaping their life trajectory in response to what is happening around them (Thornhill et al., 2004; Andersson et al., 2015; Marriott et al., 2019). When considered in this way people with psychosis' beliefs and attitudes towards their 'symptoms' and social experiences, and the concomitant behaviours, such as withdrawal, demonstrate considerable nuance and resilience in response to challenging environments. This is far removed from the medical interpretations of psychosis that interpret these beliefs, attitudes, and behaviours as social and emotional deficits to be treated through therapies both pharmacological and otherwise.

The reasons why people with psychosis face such challenges relating to others was not explored as part of the interview, or analyses, process. Research and discussion into this area is extensive and several factors have been identified. People with psychosis have commonly experienced interpersonal trauma (Mauritz et al., 2013), which can make relating to others seem threatening and shame inducing (Unthank, 2019). Frequently people with psychosis are traumatised, or retraumatised, by a powerful and coercive mental health system (Thornhill et al., 2004). Stigma plays a multi-faceted role in the relationship between the person with psychosis, the mental health system, and wider society. Certain unusual experiences, such as voice hearing or ideas

that others do not share, are labelled as problematic and possibly dangerous, and ways of understanding these experiences, for example as problems of life or as unique enlightening experiences, are closed off (Thornhill et al., 2004; Huggett et al., 2018). This stigma is internalised leaving people with psychosis feeling that they are different and incoherent (Corrigan & Watson, 2002). Consequently, people with psychosis are often isolated lacking co-collaborators in their journey through life, making their struggles even more challenging. Whilst not discussed, all these experiences were evident in the sample of participants in the empirical paper. Claire reflected on the relationship between her sensitivity to the uncertainty and insecurity of the pandemic and her experience of parental neglect and then the care system when she was a child. Both Carl and Charlotte had times during the pandemic when their distress was medicalised against their better judgement. All five participants, but particularly Deiniol and George, experienced a high level of shame associated with how they believed others perceived them.

These results suggest that supporting the client to idiosyncratically shape their life trajectories in response to difficult experiences is an essential quality in the provision of high-quality services. People with psychosis will respond to the same situation differently, but in a way that makes sense to them. People with psychosis, like everyone, will be orientated in this process towards finding a balance of autonomy and connectedness, with the fulcrum in a different place for each person, at different points in their lives. Therefore, the role of the effective service is to provide time, space, and support for people to understand their experiences. Time, space, and support which is often lacking in other areas of their lives. Charlotte's experience of the mental health system was an example of where this relationship worked well, she was provided support at the time that she needed it most as well as being encouraged to challenge and push herself. Carl's experiences were the opposite, he felt consistently ignored and misunderstood, which contributed to his sense that the pandemic had kept him stuck and unable to change.

However, the idea of the service user as actively engaged in managing the relationship between themselves and their environment, idiosyncratically creating their life trajectory in response to their experience is not something that can easily be evaluated by standardised measures of behaviours or attributes. Such standardised measures are normative, an attribute is either desirable or not, not relative, useful to some people, at some point, but not at others. As discussed in the literature review, helping people with SMI reconnect to their social surroundings is generally considered, by both mental health services, and service users, to be



an important aspect of recovery. However, the results of the empirical paper suggests that this process of re-emergence is fraught and associated with distress. Consequently, withdrawal is occasionally the preferred and, in some circumstances, the most functionally appropriate outcome. This is also true at the level of cognition. Quantitative analyses of attitudes and appraisals in psychosis often use dysfunctional attitudes scales (Weissman & Beck, 1978) in which certain attitudes are decided a priori to be either functional or not. However, given the situations that people with psychosis find themselves in, an attitude such as ‘if I fail at my work then I fail as a person’ may be both an accurate appraisal of a person’s life and history to that point, and functional in the role it plays in the individual’s behaviour. This was evident in the empirical paper, George’s appraisal of himself as weak and in need of discipline was instrumental in his process of recovery. This is possibly one of the reasons that attitudinal research in psychosis can provide mixed results (Horan et al., 2010; Berry & Greenwood, 2018)

These findings raise some interesting questions for the way the literature review was carried out. It seems reasonable to assume, given research on those that suffer with psychosis, that social functional outcomes are clinically valid indicators of treatment success. However, was it reasonable to assume that standardised outcomes will be consistently valid across a sample? It certainly seems reasonable to question whether increases in variables such as times-use and social contact will be associated with concomitant increase in subjective measures of social function; life satisfaction may increase in one area but decrease in another as behaviour changes.

Likewise, when thinking about the impact of the pandemic it is not possible to say that certain governmental interventions had a positive or negative impact on people with psychosis. This very much depends on what happened to the person, how much it interfered with, or supported their way of being in the world, and how they interpreted the changes. However, what is likely, given the propensity to need to marshal the boundary between themselves and others, the churn the pandemic produced will have increased levels of uncertainty, anxiety, and discomfort.

## **Implications for theory development and research**

Despite the questions raised so far, evidence-based research and evaluation plays an important role in the provision of mental health care. Identifying interventions that are useful and ensuring that these interventions are provided universally across teams and regions, increases the quality and accessibility of care and is a process in which clinical psychology is heavily involved.

One possible way to resolve the tension between the idiosyncrasies of human thought and behaviour and the needs of evidenced based research is to move away from concept of norms that are consistent across both life cycle and variations of human experience. Instead, evaluation could be more sensitive to the concept of developmental trajectories and stages of growth. For example, in their systematic review and narrative synthesis of research on the personal recovery construct Leamy et al (2011) identify a five-stage journey which maps on to the transtheoretical model of change: precontemplation, contemplation, preparation, action, maintenance and growth (DiClemente & Prochaska, 1998). Across these five stages five processes operate: connectedness, hope and optimism, identity, meaning of life, and empowerment. These processes are not necessarily linear, for example ‘connectedness’ may relate to moving from dependence to autonomy, or later in recovery, from autonomy to the interdependence of mutually supporting relationships. Likewise, it is possible to move backwards as well as forwards along the stages of change. Considered in this way recovery is not a fixed point but a process of development in which people are consistently engaged. At times, this process may be focused on maintaining equilibrium, at others growth and change. This appears to be similar to concepts in developmental psychology where even points of relative stability require dynamic interaction between the various systems of human function such as the psychological, social, and physical (Bronfenbrenner, 1992; Overton, 2015). Major life changes lead to disruptions in one or more systems requiring the need for reorganisation and therefore growth.

Considered in this way services and interventions would be focused on supporting the service users to attain the developmental goals relevant to them in the situation that they find themselves in. Evaluation methods that are sensitive to the preferences of the service user, whilst still providing an overall score to enable aggregation and comparison, have been developed and may be suitable for this purpose. For example, Goal Attainment Scaling

(Turner-Stokes et al., 2010) and Personal Primary Outcome measures (Leamy, Le Boutillier, et al., 2011) whereby service users are able to choose their own goals, or the outcome domains that are most relevant to them, as the indicators by which the intervention will be evaluated for them. Alternatively, the INSPIRE measure (*INSPIRE*, n.d.) could be considered. This has a series of standardised items related to mental health service use but only the scores of items that are first designated as important by the service user are compiled into the aggregate score.

### **Implications for Clinical Practice**

As described above the results of the empirical paper builds on the work of the recovery movement and others (Slade et al., 2014) in re-emphasising the importance of mental health services as spaces where people can go to try to make sense of their experiences and decide on the appropriate course of action. These discussions should not be based on the idea that there is one truth, but instead must be sensitive to the words, terminology, and global meaning used by service users. This does not mean that concepts such as psychosis should be thrown away or that certain attitudes, ideas, or behaviours should not be considered problematic or dysfunctional. However, it recognises that there can be multitude of ways of piecing together experiences into a coherent whole, and each way is of value. Importantly decisions about how experiences and behaviours are interpreted should be sensitive to development and development goals, mental health services should not be focused on making people ‘better’ but instead supporting them through their current process of development. This is a radical suggestion which would be difficult to implement given services orientation towards simplification and standardisation. However, the technologies in terms of measurement (described above) and treatment exist to support this change. Radically new treatment options are not required as the interventions currently recommended such as cognitive behavioural therapy (CBT) and family therapy (National Institute for Health and Care Excellence (NICE), 2014) and others with emerging evidence such as Acceptance and Commitment Therapy (ACT) (Wakefield et al., 2018) give room for the development of shared meaning and are built around the goals of the client. The results from the literature review suggest that these interventions should take a broader focus and consider the relationships the mental health team, and the service user, have with the wider community. Mental health teams, and individual therapists, can play a role in leveraging these relationships for the benefit of the service user. Particularly in supporting members of the community to provide the scaffolding required for individuals to re-emerge into their social environments at the moments that suit them.

Finally, much has been said about the impact of the Covid-19 pandemic on the mental health of the population. In Wales, the government is committed to increasing access to mental health services for those in need as a consequence of the pandemic (Welsh Government, 2020). Whilst access to services is important, and welcomed, this does not take into account the network of relationships and activities that are central to maintaining the wellbeing of people with SMI. What the results of the empirical paper show is that, given the challenges that this group of people face in engaging in society, even small changes to the way it is organised can have a huge impact on levels of distress. Therefore, clinical psychologists and mental health teams need to play a role in communicating to the government that the impact of changes to the way we work, travel, and socialise could have far reaching implications for people with SMI. Funding should also be provided to support people with SMI so that any changes can be navigated successfully, and even be used as opportunities for growth.

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## **Appendices**



## ***Appendix 1 Example Search Strategy for MEDLINE***

**1** ((social adj1 (participat\* OR engagement OR inclusion OR networks OR support OR contact\* OR recovery OR intervention)) OR (community adj/1 (participat\* OR engagement OR inclusion OR networks OR support OR contact\*)) OR ((neighbourhood OR neighborhood) adj/1 (participat\* OR engagement OR inclusion OR networks OR support OR contact\*)))):ab,hw

**2** (((serious\* or sever\* or endur\* or persist\* or chronic\*) adj2 mental\* adj2 (ill\* or disorder or disability or handicap or distress)) or Psychiatric ill\* or Psychiatric disorder or Psychiatric disability or Psychiatric handicap or SMI or ((depression or depressive) adj3 (major or sever\* or serious\* or endur\* or chronic\* or persist\* or resistant)) or schizophreni\* or ((bipolar or bi polar) adj1 (disorder\* or depress\* or ill\*)) or (psychotic\* or psychosis or psychoses) or (schizoffective or schizo-affective) or (hypomania\* or mania\* or manic)).ab

**3** (trial or control or control\* or experimental or placebo-controlled or placebo or double blind or single blind or matched or follow\* up or random\* or non-random\* or nonrandom\* or quasi-random\* or quasirandom\* or quasiexperimental or quasi-experimental or cohort or comparative stud\* or evaluation stud\*).ab

**4** ((animals/ not humans) or comment/ or editorial/ or exp review/ or meta analysis/ or consensus/ or exp guideline).mp

**5** hi.fs. or case report.mp

**6** 4 AND 5

**7** 3 NOT 6

**8** 1 AND 2

## Appendix 2 Assessment Risk of Bias (Quality) Checklist (Downs and Black 1998)

		REPORTING										EXTERNAL VALIDITY			INTERNAL VALIDITY													POWER			
	Question No:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	Tot'l	%
PEER SUPPORT																															
1	Chinman et al. (2013)	1	1	1	1	1	1	1	1	0	1	1	1	1	1	0	0	1	1	1	1	1	1	1	1	1	1	1	0	24	86%
2	Craig et al. (2004)	1	1	1	1	1	1	1	1	0	0	0	0	0	1	0	0	1	1	1	1	1	1	1	1	0	0	0	0	17	61%
4	Felton et al. (1995)	1	1	1	1	1	1	0	0	0	1	0	1	1	1	0	1	1	0	1	1	1	1	1	0	0	0	0	0	17	61%
5	Klein et al. (1998)	1	1	1	1	1	1	1	0	0	0	0	0	0	1	0	0	1	1	1	0	1	1	1	1	0	0	0	0	15	54%
6	Mahlke et al. (2017)	0	1	1	1	1	1	1	1	1	0	1	1	0	1	0	0	1	1	1	1	1	1	1	1	1	1	1	0	22	79%
7	Rivera et al. (2007)	1	1	1	1	1	1	1	1	0	0	0	1	0	0	0	1	1	1	1	1	1	1	1	1	0	0	0	0	18	64%
BEFRIENDING																															
3, 8	Davidson et al (2004)	1	1	1	0	1	1	1	1	0	0	0	0	0	1	0	0	1	1	1	1	1	1	1	1	0	0	0	0	16	57%
9	Priebe et al. (2020)	1	1	1	1	1	1	1	1	0	0	1	1	0	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1	24	86%
10	Sheriden et al (2014)	1	0	1	1	1	1	1	1	0	0	1	0	0	1	0	1	1	1	1	1	1	1	1	1	0	0	0	1	19	68%
SHARED ACTIVITY																															
11	Stein et al. (1995)	0	1	0	0	1	1	0	1	0	0	0	0	0	1	0	0	1	1	0	1	1	1	1	0	0	0	0	0	11	39%

		REPORTING										EXTERNAL VALIDITY			INTERNAL VALIDITY													POWER			
	Question No:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	Tot'l	%
RECOVERY AND REHABILITATION THERAPIES																															
12	Bitter et al. (2017)	1	1	1	0	1	1	1	1	0	0	1	1	0	1	0	0	1	1	1	1	1	1	1	1	0	1	0	0	19	68%
13	Fowler et al. (2009)	1	1	1	1	1	1	1	1	1	1	1	0	0	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1	25	89%
13	Fowler et al. (2019)	1	1	1	1	1	1	1	1	1	1	1	0	0	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1	25	89%

#### QUESTIONS:

REPORTING	EXTERNAL VALIDITY	INTERNAL VALIDITY	POWER
Q1 = Presence of a hypothesis relating to social functional outcome Q2 = Social functional outcomes clearly defined Q3 = Participants clearly defined Q4= SMI clearly defined Q5= Intervention clearly defined Q6 = Distribution of confounders clearly defined Q7= Findings of interest clearly presented Q8 = Estimates of variation provided Q9 = Adverse events reported Q10 = Lost to follow up described Q11 = Actual probability values presented	Q12 = Recruitment representative Q13 = Participants representative Q14 = Treatment centres representative	Q15 = Participant blinding Q16= Measurement blinding Q17 = Evidence of data dredging for functional outcomes Q18 = Differential follow up adjusted for Q19 = Statistical test appropriate Q20 = Evidence of compliance issues that favour the intervention Q21 = Outcome measures appropriate Q22 = Recruited from the same population (selection bias) Q23 = Recruited over the same time period (selection bias) Q24 = Randomisation Q25 = Randomisation concealment Q26 = Adjustment of confounding Q27 = Adjustment for loss to follow up	Q28 = Power calculation for functional outcome

### **Appendix 3 - Excerpts from reflective journal on interview and narrative / thematic development for Claire**

#### **1. Selected post interview reflections**

I warmed to her. She gave a great deal to me. I empathised with her struggle, living alone, with mental health problems, a son with learning difficulties. I also warmed to her partner, someone who is thoughtful. Willing to sacrifice own wellbeing for hers – coming to work at her house even though there was no space.

I suppose as I was working through the interview I was trying to set up situations in which she might describe to me interpersonal challenges. Narratives about interactions with other people. We managed to get to this point on a couple of occasions but it doesn't feel like very often. I suppose that I was disappointed with this. This, taken with her suggestion that there are certain things that she can't talk about in the house, led me to think that she was avoiding talking about things. I wonder how well controlled and rehearsed the narrative was. However, she did appear to be very reflective and take the time to think about the questions that I asked and be as open and honest as possible.

There was very much a linear process to that which she spoke about -start at the beginning, end at the end. There was a significant amount of analysis. One term that she used a number of times was 'mixed bag'; the pandemic had allowed her to relax and spend time on the relationships that were important to her. There was another element of the uncertainty around the pandemic that led to increases in anxiety and unusual experiences. The pandemic came in phases of certainty and less certainty. One area of certainty was the initial lockdown. Lifting of lockdowns were generally associated with more uncertainty. There were also themes that came up throughout – sense of closeness to partner but also some discomfort / regret over what she had put him through. Same with son; a closeness as well as a struggle with his emotional closeness – I just want to be on my own. Sense of closeness and distance to others was a theme throughout, physically and psychologically. Physical distance easier than psychological distance. Sometimes psychological and physical distance overlapped – for example – partner providing touch.

#### **2. Selected post transcription reflections**

This is a very coherent account of the pandemic and how it impacted on her mental health. C is very reflective able to pin point what led to deteriorations in her mental health and also why her experiences of trauma predisposed her to experience the pandemic in a certain way. I wonder if there is an attempt to gain control of the uncertainty through providing a coherent narrative. It's understandable that I would think that way if I was under stress other people were / are also quite paranoid. When things become more stressful the coherent narrative falls apart??

Despite this I have a very clear sense of what was important to her and to some degree her relationships, underneath there is a sense of uncertainty – for example her fears that everything will be taken away, perhaps she has asked too much of her partner. E.g. self harming after the first lockdown feels slightly incongruent with the certainty and closeness of her relationship with her partner during the lockdown. In my mind I think that it would be clear that the lockdown has demonstrated how close your relationship is.

There is also a decisive / purposeful element to the story which contrasts with the focus on reliance on others (for example I trust my boyfriend it was his idea to stock up on food and take son out of school). For example she talks about taking son out and putting him back into school despite concerns about the virus.

Her fight is one for control 'I don't know how I would have coped if I'd not had the consistent financial support of benefits over the course of the pandemic'. The pandemic kind of took away control of one aspect of peoples' lives and delivered it in other. It gave heightened control over personal relationships. It took away a sense of control over other parts of lives – schooling / health support / finances.

### **3. Selected post narrative summary reflections / structure of the narrative**

#### **Connection to people –**

**Themes** – proximity (both physical and psychological), trust, expectations of others.

C generally sets herself up as a passive recipient of changing relationships and situations around her. For example early in the account she describes how her partner 'who she trusts' advises her to prepare for lockdown. Partner comes to stay during the pandemic but no information is given on how that decision is reached 'my partner came to stay'. C makes a strong point about how her relationship with partner and son increased but again this is due to the situation around her, the lack of pressure from the external world.

As uncertainty around Christmas increases, passive to the decisions that others in power are making, as she (actively) searches for solutions and understanding which culminates in two unusual experiences. This is evaluated as being passive to both the uncertainty of the situation and her past trauma. Also evaluates that she is similar to others in this regard 'other people were believing conspiracy theories at this time'.

At the end of her narrative and report on how things had developed for her over the course of the pandemic, C delivers a narrative on how she was concerned how she was going to cope after Christmas with her son's school closed. The climax of this narrative is that she asks for a school place for her son. This is one of only two clear descriptions C provides of her actively intervening in a relationship. However this narrative is evaluated in terms of being put into a difficult position of having to choose between physical safety and mental health.

#### **Wellbeing:**

**Themes:** Support, boundaries, (in)consistency (un)certainty, and channelling anxiety

Initially provides narrative on preparation and how this helped to manage her anxiety (which is a problem for her). Deciding, despite her misgivings, to listen to others and prepare. There was uncertainty outside but I was prepared.

Initially focuses on certainty at home vs the uncertainty (which she emphasises) outside. Her report of the initial lockdown focuses on the contrast between these two. This is partially a product of the situation, rules about socialising and her partner coming to stay, and partially her decisions and actions. Making sure that everything is cleaned coming into the house. Not speaking about destabilising topics inside the house.

In the final part of her initial description of the lockdown / pandemic she describes how she decides to send her son to school, despite the uncertainty, in order to preserve her own mental health. This is the first time she acknowledges embracing some uncertainty in order to look after her own mental health. However she doesn't describe any learning that has come from this. She completes the narrative / report by saying that 'it is just one thing after another' – perpetual inconsistency / inability to plan and describing her inability to take time out from the pressures of her day to day life (is this something to do with opportunity to break routine?) loss of control.

At the end of the narrative and report on her experience of the pandemic come a series of evaluations and augmentations. These follow the pattern of the narrative report (background worries vs improved relationships and reduction in support) apart from two of interest. One on self development, learning about coping, which doesn't appear during the narrative / report. One about feeling that her situation is similar to others and this both helping and increasing distress. This suggests that this is not just a tale about what has happened so far during the pandemic but an attempt to describe to me, independent of narrative, what her internal experience has been like.

### **Purpose**

**Themes:** Getting through, pressure to do things, getting things done, contributing, focusing on mental health.

Initially narrative / report focuses on getting through and the decisions she takes to manage. However, a by product of having less pressure to do things, is increased quality time with son and partner. As lockdown lifts she reports more pressure to do things and the decrease in quality time. As lockdown lifts that getting things done are more engaged, particularly around the manic episode. C evaluates (presently) that these manic episodes were productive. However, the narrative is of one of being out of control. Out of control productivity. A pressure to be productive, is this linked to her contribution which she evaluates at the end as having (appeared to) decrease over the course of the pandemic? The focus on mental health is generally stymied through poor support and erosion of routine (evaluation / augmentation at the end). However a brief augmentation / evaluation of finding out more about coping strategies.

***Appendix 4 – Selected excerpts from ‘Claire’s’ interview transcript to illustrate the process of developing Biographical Data Chronology (BDC)***

**Excerpt from interview 1**

2	Me: initial question
3	HC: ok.....
4	Me: go ahead
5	HC.... ok so erm .... erm... I think erm the first that I think I felt.. when... erm.. we ... sorry I'm all tongue tied.
6	Me; take your time, it's difficult, I appreciate I appreciate this effort you're putting
7	HC... ok... erm I think at the beginning it felt really surreal soo... when it was kind of, you know, it was emerging in China and those couple of months where erm you know C 19 was around but you know it wasn't here it wasn't a pandemic yet. ERm... I don't know it was kind of... it just felt really surreal erm. <b>can remember a friend saying to me about how you know 'you sh., you need to stock up on food' and I can remember... erm... Thinking that that she was erm... you know that that was really excessive</b> and and stuff like that really and thinking that nothing was really going come of it... erm and then I guess like, it started getting a bit more serious and there started being cases in the uk and stuff like that... erm.. and I think really.... erm... .. yeah.. a couple of weeks before the erm the lockdown the national lockdown was announced erm.. my my partner, my boyfriend, we don't live together but we've been together five years, erm.. <b>he said you know 'it's getting really serious now we need to erm we need to take my son out of you know take my son out of school and we need to start getting tins in and stuff like' erm so we actually did that a couple of weeks before the. the national lockdown was announced erm and at the time, you know, I still thought a bit kind of excessive but erm I trust my boyfriend, I trust his opinion, erm and I kind of felt like it was good to be prepared...</b> erm,,,so I have a lot of anxiety anyway and I think it was really good to have somewhere to kind-of direct it erm yeah so it felt really good to be prepared and then when the national lockdown was announced it was kind of a relief really... erm... but we had been prepared for it for maybe 3... 3 weeks before.. erm... yeah... an just it all just felt really surreal at the beginning erm I can remember the first time we went out for a walk for our exercise and the streets were empty and... I don't know It just felt like something had..you know..all the shops were empty, everybody was wearing masks it felt like erm it was from a film really from like erm ... i don't know 28 days later or something
8	me: laughs
9	HC: erm yeah it was really disorientating erm... yeha.. ..'
10	me: ok
11	HC: yeah.. so that was kind of yeah.... that was how I felt at the beginning
12	me: mm erm yah thanks for that it was really useful

Distinct event – told to prepare.

Story point 1

Distinct event – told to prepare. Analysis it felt good to be prepared.

Story point 1

13	<p>.....erm yeah so erm during the first lockdown erm my partner came to stay erm which I don't think I would have got through it without him really he came and he stayed for the full I think it was about 12 weeks where we were in a proper lockdown.. erm.. and that was really nice to have him here like to have his physical like his company, his physical support and emotional support as well erm so... and my son erm was obviously home from school well he was home from school during the first lockdown erm.. so there was like a lot of changes erm..... which erm... yeah... erm..... it was erm..... it wasn't too it wasn't it wasn't too bad really during the first lockdown because I did have my partner here and we were able to support each other and we kind of got into into a bit of a routine I did actually find I was really worried about the virus er... like my ocd got really became really bad with checking things, erm not just hygiene things, er, but I was we were really careful erm we were really careful erm so you know like even taking shoes off before we came into the house and I would take them into the back garden you know we were..... washing our hands a lot.. you know.. when we had food deliveries an things like, you know, wiping everything down and stuff, err... we wore masks when we were outside even though it wasn't like government recommended...erm... so I did feel really anxious erm and it kind of spiralled from there really so then I was you know obsessively checking the door was locked and things were switched off erm..... and kind of felt like at the beginning when we were preparing for it there was like somewhere for my anxiety to go..erm...but then we were kind of, you know, trapped at home stuck at home and.. it felt like..... you know there was all this anxiety and this tension and felt it should be let out in some way and I guess I couldn't really erm... let it out..... erm in that way..erm... so yeah so that was quite bad during the first lockdown but we didn't... you know..... erm.... yeah it like I think it was really good to have like the support of my partner and we did we did have some really good times as well and some good memories and it was it was really nice erm... I think erm... I found it really hard having my...like my support disrupted erm during the first lockdown erm... I was working with the early intervention for psychosis team.. and we were kind of at quite a critical point in the therapy erm.. and we were talking about things that were.. that I wan't happy to talk about at home over the phone it was things that I felt I needed to talk about in person and out of the house because the house is my safe space... erm.. so.. that was really difficult to.. kind of.. have to put that on hold for a while erm... I also noticed that it affected other support I had erm.. from the community mental health team and support that I had for.. for my son as well who has learning difficulties he was discharged from a lot of places...erm..... so that was difficult..erm..... and I guess you know even little things like like having to go and pick up, you know, I take medication for my bi-polar and having to go and pick up the prescription once a month that was quite stressful because I felt quite anxious about going outside and going into the shop and stuff... erm... so there's kind of like a lot of stuff going... going on.. but we did have lots of good memories, you know, it was nice in some other, in in a lot of ways as well because we got to spend more time together we were doing fun activities together and there wasn't stress of everyday life, so even though we had this big picture stuff in the background I felt less</p>	<div>Distinct event – Partner comes to stay. Analysis it was nice / support Story point 2</div> <div>Distinct event – Son comes home from school. Story point 2</div> <div>Period of time – Routine during the first lockdown. Story point 2</div> <div>Period of time – worry/anxiety/ ocd during the first lockdown. Story point 3</div> <div>Period of time – support from partner / good times and memories during the first lockdown. Story point 2</div> <div>Distinct event – support stopped/reduced . Story point 3</div> <div>Series of events – anxiety at picking up medication . Not used</div> <div>Period of time good memories / reduced stress Story point 3</div>
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	<p>less anxious you know I wasn't getting stressed about erm having to go out erm... socialise on bad days and stuff like that really erm... I think for me the food insecurity when all the the shops started selling out of stuff that was a really big thing for me erm.. I come from like a trauma background and erm when I was a kid I didn't always have enough food and stuff like that.. erm.. so I kind of noticed that was a big stress, that was really really stressed me out that kind of erm at that point we didn't have a car either so that kind of stress to get an online shopping slot erm... erm that really really affected me and kind of brought up a lot of things for me it was very difficult erm.. but so it was really kind of a mixed bag. erm The experience that we had as a family. it was really nice to have my partner stay. it was really nice to have some quality time with my son. he has.. learning difficulties which means that he finds transitions really hard so he kind of thrived on on this routine we had at home where everyday was the same erm.. and we had some really good times and made really some good memories but then at the same time there was a lot of anxiety and a lot of big picture stuff going on..erm..</p>	<p>Period of time worries about food security</p> <p>Story point 3</p>
14	<p>and then I think when the lockdown started to ease up ... erm.. it was like a big change again to get used to erm... that kind of yeah that was really hard my son went back to school it was just erm.. they did like erm a couple of morning session a week erm where there was just a couple of them in at the same time erm... and erm yeah it was hard to get back in that that routine and my partner went home and erm I'd actually really started struggling then erm... like I had a big like increase in like self like how much I was self-harming erm.. and it was it was quite was quite difficult for a while erm... and then we started getting in to more of a routine again and we kind of really enjoyed you know the weather was really good and went and you know we'd go for a big long walk in the morning erm and then we'd have lunch we'd we'd kind of got into a routine where you know in the afternoon we'd do our own things and stuff me and me son so..., yeah it kind of erm, yeah kind of we started getting into a nice routine again and that was nice we started doing socially distanced walks with friends as well and I found that much easier erm having like one on one time with with my friends rather than meeting in a group that kind of thing there was less like social anxiety erm... I did notice that I still had quite a lot of anxiety built up and I actually had quite erm.. over the summer I had quite a few hyper manic episodes erm... which erm. I'd definitely say there was like more than I normally have, really, erm... I think like that the episode that stands out the most for me is was erm what I dubbed the 'painting episode'</p>	<p>Distinct event – son went back to school</p> <p>Story point 5</p> <p>Distinct event – partner went home</p> <p>Story point 5</p> <p>Period of time – self harm increased</p> <p>Story point 5</p> <p>Period of time – routine and socially distanced walks with friends</p> <p>Story point 6</p>
15	<b>Me:</b> laughs	
16	<p>which is where I got really kind of obsessed with painting the front of the house... erm.. but it was really really excessive I erm you know I wouldn't stop if it rained, I wouldn't stop painting the doors I was hanging out of the upstairs windows erm.. I kind of went on for a.. good couple of day I actually painted the front door so much that it wouldn't close there was (laughs)) so many layers of paint on it.</p>	<p>Period of time – hyper manic episodes</p> <p>Story point 6</p>
17	<b>Me:</b> erm	<p>Distinct event – painting episode</p> <p>Story point 6</p>

### Excerpts from interview 2

41	<b>me:</b> Quite early on in the description you talked about your partner
42	<b>HC</b> Yeah
43	<b>me:</b> in the early days and then later on as well. Can you describe a particular time, occasion, or incident involving your partner during lockdown?
44	<b>HC</b> Like how he supported me?
45	<b>ME:</b> It's really up to you what you decide to talk about, anything that stands out for you I suppose.
46	<b>HC:</b> I don't know, just the whole experience of having him here like, I don't know. just how he would be supportive like the first time I had to go and get my prescription I was really really nervous about going to the pharmacy we kind of, all three of us, my son as well. We walked to the pharmacy and we kind of erm.. you know, I was going in and get my medicine but it was just really clear that I was you know I was going I was really really anxious and erm... instead of my partner and my son waiting outside my partner went in and got the prescription for me erm.. and I think that was just like..... yeah... it was just really nice.. because he felt like he was just really sensitive and like aware of how I was feeling and what I was anxious about..erm. so I guess it was like giving me that kind of practical support.....
47	<b>me:</b> ok
48	<b>HC.</b> but I have I have other examples (laughs)
49	<b>me</b> laughs yeah is I mean is there anything else? that was what I was after really a little description of what went on. Is there anything else that you think is important about these events indicative of your relationship with him
50	<b>HC.</b> yea I think like, just loads of things, really like I just kept feeling really really overwhelmed and I didn't know where to start things he would just do little things like he might put all the washing up into order so like the bowls are all together on top and then the plates and the cutlery to one side in a container so I knew where to start, he, I think that the physical contact was really important as well er... like just giving me a hug and letting me know that everything's is ok when I was struggling really erm.. and just being there. Erm you know I I think it was like a big sacrifice, he he worked from home before the pandemic anyway erm.. but when he came to stay he. there was no where for him to work apart from the cupboard under the stairs and erm I think that just knowing that he was there if things got too much... and I could just like knock on the door and that we was just, you know, he was there and I wasn't alone it was really really important.
51	<b>me</b> I hope that I'm not prying too much here. I just interested in that sense of touch. You talked about physical contact. Is there a memory when you got physical contact from him.

Distinct event – going to the pharmacy with partner

Not used

Period of time – partner providing support

Story point 2

52	<b>HC</b> yeah erm. the first thing that comes to mind is like the first walk that we went on when we when we to do go out for our exercise once a day and erm and you know everything was really different and there was nobody around, erm,.. it was empty, like I think I said before like 28 days later kind of style, just no cars or anything erm.. and yeah he just took my hand and held my hand and I just felt, I don't know, yeah really reassured (laughs)
53	<b>Me</b> ok ok great thanks for that. Don't feel that you need to say anything more about your partner. Is there any particular occasions or events that you can remember?
54	<b>HC</b> No I think the most imp... I think the big thing for me is when we decided that he was going to stay for the first 12 weeks. It was really really imp I don't know how I would have coped with those first 12 weeks without him really erm.. so I think just having having his .. physical an emotional support really was really important.

108	<b>Me</b> Ok erm. thank you. A couple more things. Towards the end you started to kind of the initial discussion that we had you started to reflect a bit more on what the pandemic has taught you and meant for you. I was interested in this idea of comparing yourself to others... one of the things you mentioned was comparing yourself to others. Sometimes more difficult and sometimes easier. Describe a particular time when you were aware of things being more similar to other people
109	<b>HC.</b> erm.... yeah.... just kind of in conversations with people friends that don't have erm.. don't don't have any diagnosable mental health conditions you were you know you were really kind of..... talking about their anxiety you know their anxiety about pandemic and about about change and talking about... maybe... you know... the way that it had affected them and I can remember just sitting there and listening and thinking 'you know 'yeah like people you know really... people know this is they und... they're like really feeling the same kind of anxiety as me erm... yeah....
110	<b>ME</b> ok again you talked about one conversation to mind that you had
111	<b>HC</b> yeah yeah just talking to one of my friends on the telephone really erm..... and she was you know she was just talking alot about how...I don't know I can't I can't particularly remember the conversation but I can remember the feeling that I had erm just that sense....that I really I didn't feel alone that I felt I could really empathise with her erm... and I felt that she empathised with me
112	<b>ME</b> ok ok you said the opposite as well that other people were also responding quite differently from you during the pandemic and the lockdown you mention friends that were doing things and home games and decorating
113	<b>HC</b> Just going back... yeah
114	<b>ME</b> yeah

Specific event – conversation with friend on phone talking about mental health

Story point 4

115	<b>HC</b> Just going back to the one before as well
116	<b>ME</b> Yeah
117	<b>HC</b> About the similarity I think it was reading about stuff in the newspaper as well you know when I was reading about people that were struggling with to to you know to work or that they'd been made redundant erm they were on furlough like and a lot of my friends were on you know had been put on furlough and they'd got those financial worries or work worries, you know they're worried I don't know just that sense really that everyone was struggling in some way..... but it not's specific but it felt like important to kind of say.
118	<b>ME</b> yeah thanks erm
119	<b>HC</b> and then
120	<b>ME</b> Erm
121	<b>HC</b> and then going back to the differences erm I think it was just like, I don't have erm, I don't have facebook or or instagram or anything like that erm but I was in touch a lot more. I've been in touch a lot more with friends over... over WhatsApp actually and erm... you know I can remember there was a day when I was feel really really rubbish like everything you now... I was just feeling really down erm I was I was feeling really low I had no energy it was a struggle to brush my teeth and there was just you know my friends sending me pictures of them them playing boardgames with their kids, them homeschooling their kids, erm I think it was just unfortunate that a lot of people just decided to do this on the same day (laughs) erm and you know pictures of them gardening or decorating and just everybody talking about these productive and.... all this stuff that they were doing erm... and like... you know and how nice it was not to work and all this stuff and it just kind of it made me feel really like.....I don't know I was just like looking at all the pictures and just really felt like that I should be doing more.... I should be doing the same as other people like why aren't I making the most of this time, why aren't I enjoying home schooling, like erm just you know kind of feeling like really down about myself..... I felt like other people were coping better than me... I felt like I should be doing more.....
122	ok anything more that you wanted to say about that
123	no

Specific event – WhatsApp messages – others coping better

Story point 4

*Appendix 5– Adding Key Events and Time Periods on to Covid-19 timeline and selecting events for the Biographical Data Chronology (BDC) for ‘Claire’*

		INTERVIEW 1			INTERVIEW 2		
Mar-20	SP	Distinct events	Ongoing events	Impact on mental health / wellbeing	Distinct events	General events	Impact on mental health / wellbeing
first C-19 case in Wales (28/2) (11/3) NHS appts (13/3) shielding / self isolation starts (16/3) schools close (18/3) full lockdown begins (23/3)							
	S1	told by others to prepare					
	S1	took son out of school / bought tins		glad to be prepared			
	S2	partner comes to stay and stays for first lockdown	routine develops	good to have partner's support	shopping inc. medication / physical support		
	S3						Worried about food running out
Apr-20							
PM states UK passed the peak (30/4)	S3			worries about virus			
	S3			OCD became worse			
	S3						worried about son's neglect as n
	S3		son stopped getting support				
	S3		Reduced support from mental health services				
	not counted					son wants to be close all the time	agitation
	Not counted		Having to get medication				
	S4					friends talking about their anxieties over money / health	
	S4					whatsapp messages of friends	down about self
	S3		spending time together as a family	Happy memories			
	S3		Struggled to get delivery slots from shops	Stressed			

## Appendix 6– Interpretive Hypothesis and following Hypothesis Generation in the development of Claire’s Narrative Summary

Key: **Hypothesis supported** / **Hypothesis Refuted**

**What am I trying to do here?**

*I am looking at how events may structure experience of the pandemic in terms of connection to others, wellbeing, and sense of purpose. At the end of this exercise I should have a structure of the lived life of the pandemic relating to these three areas. Four or five key turning points where experience either changed course of later experience (or re affirmed current course)*

*Later actions serve to support or weaken hypothesis.*

**Story point one:**

(About) Two week before the lockdown HC is told by others, including boyfriend, to prepare. She takes her son out of school and stocks up on tins. She describes herself as glad to be prepared when the lockdown starts.

This point refers to sense of connection – taking (useful) advice from others and withdrawing from society.

How might this event structure her experience of connection to other during the pandemic?

**Hypothesis 1** – she may experience this as successful connection and interpret it as meaning that it is important to connect to others for help and support

Folk psychology that she has some kind of underlying idea of connection (belief), belief is reinforced by the experience. Seeks to replicate these experiences. It is also based on a clinical understanding (and what she has told me) that people with traumatic childhood struggle to trust other people. This hypothesis is differentiated from the one below which posits some kind of anxious attachment, lack of confidence, need for reassurance.

Following hypothesis – she demonstrates attempts to connect and get close to others

Strengthened by SP 2 – invites partner to stay

Strengthened by SP 3 – memories of family interactions suggest activities organised as a family.

Strengthened by SP 4 – Attempting to connect with friends

Strengthened by SP 6 – socially distanced walks with friends

Weakened by SP 7 – pressure to meet up with friends – suggests resistance to this

Strengthened by SP 8 – restarting sessions with EIPS

Strengthened by SP 9 – hallucinates that she can be useful to others

**Hypothesis 2** – she may experience this as lucky escape – it’s a good job someone warned me and feel that it is essential she is looked after.

Following hypothesis – she demonstrates attempts to get close and remain close to others

Strengthened by SP 2 – invites partner to stay

Weakened by SP 3 – reduction in services with no attempt at increases in connection

Weakened by SP 5 – partner goes home

Weakened by SP 6 – socially distanced walks (distance is prioritised )

Weakened by SP 7 – pressure to meet up with friends

Strengthened by SP 8 – restarting sessions EIPS

**Hypothesis 3** – she may experience satisfaction / safety / righteousness at withdrawing from society.

Following hypothesis – she seeks to maintain separation from mainstream society.

Strengthened by SP 3 – no described attempts at reconnecting to services

Weakened by SP 4 – attempts to connect with friends

Weakened by SP – 5 – sends son back to school.

??? by SP – 7 – pressure to meet up with friends / but sends son back to school fulltime

Weakened by SP 6 – socially distanced walks with friends

Weakened by SP 7 – restarting sessions with EIPs

Strengthened by SP – 9 – believes that she is being watched by the government

Weakened by SP – 10 – sends son back to school

This point refers to wellbeing- being glad of her preparation – this suggests a sense of safety / being at ease

How might this event structure her experience of wellbeing during the pandemic?

**Hypothesis 1** – she may interpret this as preparedness brings with it a sense of wellbeing

Following hypothesis – she attempts to prepare throughout the pandemic leading to improved wellbeing or she is thwarted in her attempts to prepare and experiences decreased wellbeing.

Strengthened by SP 3 – attempts and fails to get delivery slots

Strengthened by SP 6 – manic shopping when the shops re open

Strengthened by SP 9 – seeks solution to problem reading 1984 / ‘there’s a solution in my blood’

## Story point 2

HC’s partner comes to stay at her house during the lockdown. Partner is helpful. Routine develops. HC states that it is good to have his support.

This story point refers to connection to others – relationship with partner who is helpful and supportive.

How might it structure her experience?

**Hypothesis 4** – HC realises how important this particular relationship is to her

Following hypothesis – HC attempts to maintain or increase closeness.

Strengthened by SP 3 – spending time together

Following hypothesis – HC wants increased closeness but doesn't ask for it

Strengthened by SP 5 – self harm (distress) increases when partner leaves

This story point may refer to sense of purpose – playing the role of partner.

**Hypothesis 1** – HC enjoys being a live-in partner

Following hypothesis – HC describes the development of her role as a live in partner

Strengthened by SP3- happy memories as a family

Strengthened by SP5 – increased distress when partner leaves

**Hypothesis 2** – HC doesn't like being a live in partner

Following hypothesis – HC attempts establish independence from this role

### Story Point 3

Describes the first lockdown. Reduction of services for both her and her son. Describes that it is difficult to get food deliveries and that this leads to stress. Co-occurring increase in anxiety and worry about food, the virus, and her son's wellbeing as he's not at school. OCD becomes worse. At the same time she describes happy memories of being 'together as a family' son and boyfriend.

This point refers to connection to others – happy memories of being together as a family, difficulties associated with reduction in support.

### No further hypotheses

This point refers to mental health / wellbeing – increases of anxiety and OCD relating to virus / food security / and son's wellbeing. Made more difficult by reduction in support. Also happiness of being close to family and partner.

How may this event structure her experience of the pandemic?

**Hypothesis 2** - may interpret this as lack of control of her environment brings more anxiety

Following hypothesis – seeks greater control of her environment or be thwarted in her attempts to seek greater control e.g. seeking greater support or input from services

Strengthened by story point 5 – increases distress as routine disrupted

Strengthened by story point 6 – manic shopping. Socially distanced walks – reestablishment of routine

Strengthened by story point 7 – difficulties at return of normal life – pressure

Strengthened by SP – 9 – reading 1984 'my blood can be useful'

- May interpret this as lack of coping strategies.



Following hypothesis – seek new / alternative ways of effective coping or seeks alternative ways of coping that are ineffective.

– door painting episode could be interpreted as an attempt to make the most out of the pandemic as others were doing at the time and HC had been in contact with based on her contact with

**Hypothesis 4** – May interpret this as closeness to others, particularly family brings wellbeing.

Following hypothesis – seeks closeness / relationships to others.

**Strengthened by story point 4** – Communicating with others and seeing herself as different brings a drop in mood.

**Strengthened by story point 5** - increased distress as partner goes home and son starts school

**Strengthened by SP 6** – restoring routine with socially distanced walks

Strengthened SP 9 – I can be useful to others

Weakened by SP 7 – pressure to meet up

Weakened by SP 10 – sends child back to school full time

This point refers to sense of purpose – as a satisfied family member –

How might this structure her experience of the pandemic?

**Hypothesis 3** – Finds purpose in role as a mother and a partner

Following hypothesis – Takes actions to maintain the coherence of the family unit

**?? Story point 5** – relinquishes her role as mother and partner but experiences increased distress

Story point 6 – sends son back to school full time

Story point 10 - asks to send son back to school – weakened – want to have a break. Strengthened putting his needs first

#### **Story point 4**

Describes two situations in which she interacts with friends. Once talking to a friend over the phone about anxiety and how it had affected her friend. Once receiving a series of WhatsApp messages of friends making the most out of lockdown – feels down on self in response

This story point refers to connection to others – interacting with friends about mental health. Receiving text messages with pictures of others coping well / making the most out of lockdown

How might this structure her experience of the pandemic

**Hypothesis 5** - My problems are similar to other people's (but I am less well able to cope)

Following hypothesis – seeks to engage with others, reciprocally, around mental health.

Weakened by SP 7 – pressure to meet up

Following hypothesis – seeks to cope like other people / be more like other people

Strengthened by story point 6 – manic episodes as a way of coping like others

Strengthened by story point 8 – seeks support with coping

**Hypothesis 6** – My problems completely different from others (shame or self-righteous)

Following hypothesis (shame) – seeks to hide problems from others

Weakened by SP 6 – socially distanced walks

Strengthened by SP 7 – pressure to meet up

Following hypothesis (self-righteous) – seeks to explain demonstrate how her problems are worse / more difficult to dealt with than others.

**Hypothesis 11** (suggested after SP 9) I am unable to connect to others during the pandemic

Following hypothesis – give up trying to connect

Weakened by SP – 6 socially distanced walks

Supported by SP 7 – pressure to meet up with others during autumn

Following hypothesis – seek to develop ways to connect

Supported by SP 8 – EIPS

Supported by SP 9 – believes can be helpful to others

This story point refers to mood – feeling low when comparing herself to her friends

How might this structure her experience of the pandemic

I am defective and there is no point

Following hypothesis – giving up at attempts to cope

– relinquishes roles and distress increases

– manic shopping and door painting episode / re-establishing connection with others

Strengthened by SP 7 – pressure to meet up feeling low

Weakened by SP 9 – finding purpose in 1984 and her blood

Weakened by SP 10 – asks to send son back to school

This story point refers to sense of purpose – sense of purpose as a friend or lack of purpose in comparison to friends.

**Hypothesis 4** – I have a purpose in this pandemic as a supportive friend

Following hypothesis – seeks further opportunities to help and support others

Strengthened by SP 6 – seeks to develop a routine around friends

Weakened by SP 7 – pressure to meet up low mood

**Hypothesis 5** – The pandemic has removed my sense of purpose

Following hypothesis – seeks renewed purpose

Strengthened by story point 6 – Painting episode but also weakened as seeks to establish routine around socially distanced walks

Strengthened by story point 9 – 1984 and answer in blood.

Story point 10 – sends son back to school

Following hypothesis – give up

Strengthened by story point 5 – relinquishes roles and distress increases

Weakened by story point 6 – establishes routine around socially distanced walks.

Strengthened by story point 7 – low mood (withdrawal) at start of autumn

Strengthened 8 – pressure to meet up

### Story point 5

Lockdown eased in summer. Son started school experienced reduced routine. Partner went home. Self-harm increased

This story point relates to connection to others – becomes more disconnected and this leads to an increase in distress.

How might this structure her experience of the pandemic?

**Hypothesis 1.1** – Initial distress leads affirms belief in need to connect to others

Following hypothesis - Seeks to redress the balance by bringing son and partner closer again / or seeking closeness to other people

Weakened SP7 – sends son back to school fulltime in autumn

**Hypothesis 1.2** – Despite initial distress recognises that connection cannot just be based on closeness

Seeks alternative ways to connect with son / partner during pandemic

Strengthened by SP 6 – setting up of socially distanced walks with son and friends

**Hypothesis 8** – Initial distress leads to belief that she can't cope with closeness

Following hypothesis - Seeks to push others away

Weakened by SP 6 – socially distanced walks

Strengthened – sends son back to school full time

**Hypothesis 11 (revisited)** – I am unable to connect to others

Following hypothesis – give up

Following hypothesis – find alternative ways to connect

Strengthened SP -8 – attending EIPS

Strengthened by SP 9 - sees herself as helpful to others

Weakened by SP 6 - socially distanced walks

This story point relates to wellbeing – increased distress when partner leaves and previous routine disrupted.

**Hypothesis 2.1.** – Re affirms that distress is linked to lack of routine

Following hypothesis – attempts re establish routine

Strengthened by SP6 – socially distanced walks

Strengthened by SP7 – distress as life (temporarily) return to normal

Story point 10 – attempt to re establish old routines

– Recognises that reliance on routines is too challenging

seeks to find ways of coping without routine

– painting episode interpreted as a way of coping

SP10 – attempts to re establish old routines?

**Hypothesis 4.1** – re affirms that distress and lack of closeness to others are related

Following hypothesis – attempts to reestablish connection

Strengthened by SP 6 – strengthened by socially distanced walks

Weakened by SP 7 – pressure at having to meet up

Strengthened by SP 9 – 1984 and answer in own blood

**Hypothesis 4.2** – recognises that reliance on connection to others is too challenging – seeks alternative ways of coping.

**Strengthened by story point 6** – painting episode interpreted as a way of coping

Strengthened SP 10 – sends son back to school

This story point relates to sense of purpose – previous sense of purpose has related to relationship to son and partner.

**Hypothesis 1.1 and 3.1** – reaffirms purpose in these relationships seeks alternative ways of establishing these roles

Strengthened by story point 6 – establishes socially distanced walks with son and friends

Weakened by story point 7 – sends son back to school fulltime

Weakened by story point 10 – sends son back to school

**Hypothesis 1.2 and 3.2** – looks for alternative purpose due to changes in these relationships

**Strengthened by story point 6** – painting episode as a way of coping / establishing socially distanced walks with friends

Strengthened by story point 9 – 1984 and solution in blood

Strengthened SP 10 - seeks to send son back to school

### Story point 6

During summer is shopping more, not sleeping or eating, and notices increased manic episodes inc. one relating to repeatedly painting the front door

Is doing socially distanced walks with friends and notices a reduction in anxiety

This story point relates to wellbeing – connection with friends with focus on control / distance.

**Hypothesis 9** – connecting with others is more manageable when it is restricted by distance

Following hypothesis attempts maintain distanced interactions

Supported by story point 7 – pressure at meeting up in unrestricted fashion

Story point relates to wellbeing

Manic activity associated with not eating or sleeping

**Hypothesis 1.1** – reaffirms belief in importance of preparedness – despite the costs

Following hypothesis - on-going attempts or thwarted attempts to prepare

Strengthened by story point 9 – 1984 and solution in blood

Hypothesis 1.2 – recognises the futility of focus on preparedness

Following hypothesis – attempts to accept / manage uncertainty

SP 10 – strengthened

– experiences this as productive and as improving wellbeing

attempts to maintain (successfully or unsuccessfully) high levels of activity throughout the pandemic

**Hypothesis 7** – quickly realises that this is unsustainable

seeks alternative ways of maintaining wellbeing

Strengthened SP8 – takes up sessions with EIPS

Strengthened by SP 10 – sends son back to school

Story point relates to sense of purpose – increased levels of activity

**Hypothesis 5** - the pandemic has given me a sense of purpose in terms of supporting family and preparing for the worst

Following hypothesis – further attempts to prepare are evident

**Hypothesis 7** – the pandemic has given me a sense of purpose in terms of self / home improvement

Following hypothesis – further attempts and self / home improvement.

Final hypothesis – I am struggling and need to relinquish control

## Story point 7

Autumn. Son back at school full time. Experiences pressure related to the (temporary) resumption of normal life. Including pressure to meet up with people. Experiences a period of low mood.

Connection with others – son back at school. Experiences pressure to meet up in an unstructured way

Hypothesis 9.1 – Reaffirms idea that distanced and controlled meet up are more manageable

Following hypothesis Seeks to re introduce more controlled meet-ups

Following hypothesis Wants more controlled meet ups but doesn't ask for them

Hypothesis 9.2 – Distanced and controlled meet-ups are no longer possible

Following hypothesis Seeks alternative ways of coping when meeting up in unrestricted way.  
Or is thwarted in this

Hypothesis 10 – I can't cope with meeting up with others

Seeks withdrawal from relationships

Seeks alternative ways of connecting

Strengthened by SP 9 - believes can be helpful to others

Wellbeing – period of low mood associated with pressure to meet up in unrestricted ways

Hypothesis 4.1.2 – lack of closeness to others and distress are related

Seeks alternative ways of coping in social unrestricted meeting up / attempts to re establish connections

Strengthened –SP8 – starting sessions with EIPS

Strengthened by SP 9 – 1984 and own blood

Strengthened by SP 10 – sends son back to school

– unable to cope with new way of meeting up

Seeks to withdraw

Sense of Purpose – low after son back to school and challenges meeting up with others

Hypothesis 6.1 – reaffirms the sense that pandemic has taken away sense of purpose

Following hypothesis – seeks to withdraw

Weakened SP 8 – takes up sessions with EIPS

Following hypothesis – seeks new sense of purpose

Strengthened by SP 9 - 1984 and solution in blood.

Strengthened SP 10 – decides to send son back to school

### Story point 8

Sessions resume with EIPS – things pick up

This SP relates to connection to others and wellbeing –

Hypothesis 1 (reaffirmed) and Hypothesis 4 (reaffirmed)

Following hypothesis – renewed emphasis on attempting to connect to others

### Story point 9

Plan for small Christmas (Christmas is usually a difficult time)

Uncertainty about tightening of restrictions / Brexit

Not sleeping / eating

Period of psychosis / unusual experiences

Connection to others

Unusual experiences were related to either being useful to others or being watched/controlled/abducted by others

Hypothesis – 12 – I have survived covid and my blood is helpful to others

Following hypothesis – seeks to find ways to make use of this physiological characteristic

Following hypothesis – feels paranoid seeks to withdraw

Wellbeing

Uncertainty associated with unusual experiences. Content of unusual experiences are on seeking certainty

Not sleeping / eating – reading 1984 – mania possibly seeking solution

Hypothesis 8 – the government are trying to control us / abduct me

Following hypothesis - Seek withdrawal from society / resist

Weakened by SP- 10

Hypothesis 9 – I'm really struggling and need more help

Strengthened by SP10 – decides to send so back to school

Purpose

Seeking solution to the problems of the world / seeking solution to problems of family

Hypothesis 8 – I have the solution and need to protect myself / family

Weakened by SP10

Following hypothesis - Seeks to withdraw / further preparation

Weakened by SP10

Hypothesis 9 – I have the solution I need to help / support others

Following hypothesis – seeks to help and support others

Weakened by SP10

Story point 10

Schools close but decides to ask for a place for her son

Wellbeing – needing space / time for herself

Purpose – mother – putting son's needs first – needs to be educated



**Appendix 7 Claire's Narrative Summary with notes to show thematic analysis process**

SP1		<p><b>Before Covid-19 has been declared a pandemic and before the start of the lockdown Claire is advised by others, including her boyfriend, to prepare. In response Claire takes her son out of school and stocks her cupboard with tins.</b></p> <p>At this point maintaining connection to others for help and support seems important to Claire. Claire and her boyfriend agree that he should move in.</p> <p>At this point Claire takes a sense of wellbeing in her ability to be prepared for any uncertainty to come</p>
SP2		<p><b>Claire's boyfriend moves in, she is very appreciative of his support</b></p>
SP3		<p><b>During the first lockdown support for Claire and her son, who has learning difficulties, is either cut or severely reduced. Claire notices an increase in anxiety around availability of food, the virus, and getting ill, and her son's wellbeing, given he's not at school. Claire contrasts this with happy times when her, her partner, and her son are able to spend time together in a relaxed way.</b></p> <p>Claire feels well connected to her boyfriend and son.</p> <p>Claire's wellbeing has decreased as she feels out of control of her environment. However, this is counter-balanced by the wellbeing evoked by her sense of closeness to her boyfriend and son.</p> <p>At this point Claire has a sense of purpose based on her role as a mother and a partner</p>
SP4		<p><b>During this first lockdown Claire is in contact with her friends. Claire notices that some of her friends are talking about their own mental health. On one particular day two or three friends send her photos of them enjoying themselves and making the most out of lockdown, in response she feels very down about herself.</b></p> <p>Claire feels connected to her friends, that they have similar problems to her, but that she is less well able to cope than them. Claire begins to seek alternative ways of coping.</p> <p>Given that she doesn't seem to be as engaged as her friends, Claire begins to question her sense of purpose.</p>
SP5		<p><b>As summer progresses lockdown is eased. Claire's son goes back to school part time. Claire's partner goes home. Claire's routine is disrupted. Claire's self-harm increases</b></p> <p>Claire experiences an initial increase in distress at the reduction of connection with partner and son. Claire starts to seek alternative ways of connecting to others.</p>

**Pre pandemic and first lockdown**

High levels of uncertainty  
But insulates herself from this through her close relationship / clearly defined role  
Feels both a greater sense of connection to others due to shared experiences of mental health difficulties, as well as distance – she is not coping as well

		<p>It is reaffirmed to Claire how important routine and a controlled predictable environment are for her wellbeing. Claire seeks to reinstate routine.</p> <p>It is reaffirmed to Claire how important connections to others are for wellbeing. Claire seeks to re-establish connection to others. Claire also seeks alternative ways of coping.</p> <p>Claire's sense of purpose based on her relationship to son and partner is disrupted. Claire seeks alternative ways establishing purpose.</p>
SP6		<p><b>During the summer Claire is shopping more, not eating or sleeping, has a series of manic episodes one of which is dubbed 'the painting episode'. Is also engaging in socially distanced walks with her friend(s)</b></p> <p>Claire has re established connection but with an emphasis on social distance. She recognises that meeting up is more manageable when it is distanced.</p> <p>The relationship between routine and wellbeing is again re affirmed. However, preparedness (and attempts to prepare) appear costly to wellbeing at this point.</p>
SP7		<p><b>Autumn, Claire's son is back at school full time. Claire experiences pressure related to the temporary resumption of normal life, including pressure to meet up with others. Claire experiences low mood</b></p> <p>Once again Claire's sense of connection to others has been disrupted with increases in distress. Claire experiences a need to reconnect or connect in different ways.</p> <p>Claire's sense of purpose is disrupted, and she experiences the need to find an alternative sense of purpose</p>
SP8		<b>Sessions resume with EIPS, begins to feel better</b>
SP9		<p><b>Plans for a small Christmas but still high level of uncertainty around increased restrictions and Brexit. Not sleeping and not eating. Period of unusual experiences. Claire believes she is in the book '1984' and also believes that her blood could be used to cure Covid-19.</b></p> <p>Despite temporary increases in connection to others and sense of purpose Claire recognises that she is struggling. Begins to consider ways to re establish her sense of wellbeing</p>
SP10		<b>Despite school closures decides to request a place for her son, which is accepted</b>

### Lifting of Lockdown

Initially her control uncertainty and the discomfort this causes increases. Once again she finds a way through this. Using the social distancing rules But it is more difficult. The threat seems closer to home – manic episodes

### Imposition and lifting of lockdown

Lack of consistency with rules means more uncertainty but can no longer manage interaction with outside world which previously helped with uncertainty

### Christmas and full UK lockdown

Increasing desperation leads to searches for answers. First a series of unusual experiences that are driven by a search to find purpose / certainty. Then asking for a space in school for her son to give her space and to give him extra support.

## Appendix 8 Thematic Analysis of the turning points in Claire's Narrative Summary

Converging / diverging reality	
Control / Relinquishing control	
Retreat / Re emergence	
	<b><u>Processes – over all.</u></b>
Meaning	Fight / struggle / keep going
Struggle	Certainty vs. uncertainty (struggle to maintain control)

**Key: Colour themes used in the final text**

### Summary of Claire's story

This set of events and experiences can be summarised as the (incomplete) struggle to repeatedly wrestle back control of an increasingly unstable situation. Claire faces considerable challenges but she does not give up on this task.

#### **(Turning point 1 – into lockdown)**

The initial lockdown provides relief, on the whole, as Claire finds the opportunity to connect to others in ways that she has not done before leading to experiences of wellbeing and sense of purpose. Whilst her connection to others at this point are (generally) easily structured and managed, other aspects of her environment such as access to food, support, and health are less so leading to struggles, such as that to maintain cleanliness.

#### **Processes – turning point 1**

Finding space away from others  
 Erecting a barrier from hostilities  
 – through routine and regimen  
 Others moving towards her -  
 Finding meaning and purpose –  
 happy memories

**(Turning point 2 – attempts re establish equilibrium)** Easing of lockdown initially leads to

a disruption of connection and a concomitant increase in distress. However, once again, social distance rules provide the opportunity for managed connection. Easing of lockdown leads to attempts to (re) establish control over her environment and a sense of purpose. However, these attempts are overly insistent and are interspersed with manic episodes. (Possibly conflict between continuing these attempts and seeking alternative strategies)

As restriction continue to ease Claire experiences further disruption to her sense of connection to others. Son goes back to school full time and she feels pressure to meet up in a less managed way. At this point Claire describes no further examples of attempts to establish connection, wellbeing, or sense of purpose until....

**(turning point 3 I'm struggling and need to help myself)**

....Christmas when, with uncertainty around Covid -19 and Brexit growing, Claire experiences a series of unusual experiences. These unusual experiences contain themes of connection, sense of purpose, and control as she believes she may have identified hidden governmental operations and that she may have a special role in the curing of Covid.

Despite the allure of these ideas Claire recognises that she is struggling with her mental health and seeks to re-establish equilibrium by asking for her son to have a place at school despite them being closed.

### **Processes turning point 2**

Trying developing routine

Attack / moving forwards /  
emerging – preparing / over  
preparing

Searching for control / trying to  
maintain control / rejecting  
alternatives such as acceptance

Moving towards other people  
(finding a way to be with others) /  
finding consensus

Trying to cope like others – manic

### **Processes turning point 3**

Searching for control / control  
through meaning (making sense of  
a very difficult situation)

I need this to make sense - /  
finding meaning

Engaging coping strategies /  
finding purpose – asking for a  
school place for her son

Reconnecting

## Word Counts

<b>Title Page:</b>	<b>43</b>
<b>Thesis Abstract:</b>	<b>298</b>
 <b>Chapter 1:</b>	
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 <b>Chapter 2:</b>	
Abstract	197
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 <b>Chapter 3:</b>	
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