Experiences of young people living with mental health difficulties in the context of COVID-19 and the role of integrated social care and mental health services in providing support

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Thesis Portfolio Abstract

Background: Youth is a time associated with significant change and mental health difficulties are most likely to be diagnosed between the ages of 16-25. This means there is a need to ensure that young people, particularly those with complex or social care needs, have access to the right support. COVID-19 has resulted in significant upheaval for young people and those with pre-existing mental health difficulties may have been impacted differently than the general population.

Methods: A systematic review was undertaken to identify the evidence of integrated mental health and social care's ability to improve clinical effectiveness, cost efficiency and service user experience. A qualitative study was undertaken to understand more about the experiences of young people with pre-existing mental health conditions of the COVID-19 pandemic.

Results: The review identified twelve studies which met the inclusion criteria including intervention evaluations, qualitative studies and a discreet choice experiment survey. Eleven studies took place outside of the UK. The results found evidence to support that integrated mental health and social care improves service user experience, limited evidence to support clinical effectiveness and no evaluation of cost efficiency. The empirical paper found that in young people with pre-existing mental health difficulties, the pandemic had impacted their mental health, and their responses to the pandemic had been affected by their mental health. Though this had made coping more difficult, the sample were also able to use their experiences of managing their mental health to cope with the pandemic, and for some participants the pandemic had supported them to make meaningful changes

Conclusions: The review identified that outside of improving service-user experience, evidence is currently lacking to support integrated mental health and social care as improving support for young people. Services in this area are continuing to change following the impact of COVID-19 and the development of integrated services across the NHS which may allow for further research to take place. The qualitative study suggests that young people could be well supported using a strengths-based model, facilitating developing coping skills and building on positive changes.

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Chapter One: Introduction

This introduction will provide an overview of the thesis portfolio. The chapter will begin by briefly outlining the developmental period of youth, and youth mental health. It will then describe how integrated care aims to support young people. The chapter will then consider the impact of COVID-19 on vulnerable youth populations. The rationale and aims for the thesis will then be provided.

Young people are individuals aged 10-24 years and youth is defined as the time between age 15-24 years (World Health Organisation, 2022). Youth is a period of significant development in multiple ways. Biologically, the brain experiences a surge of growth, resulting in enhanced synaptic pruning (Laviola & Marco, 2011) and significant changes in plasticity (Laube et al, 2020). As well as brain changes, independence is increased in emerging adulthood through life changes, including moving through education, commencing employment and independent living (Côté, J., & Bynner, 2008). Through this time, a young person's identity becomes more established, motivating and allowing them to seek meaningful intimate relationships (Erikson, 1963) and developing independent friendships and relationships away from family (Pulakos, 1989).

This time of great change is also a vulnerable period with 75% of mental health difficulties starting by age 24 (NHS, 2015). Disruptions during this time can negatively impact the life course in multiple ways. Threat and neglect impact brain development which can create lasting damage (McLaughlin et al, 2014). The loss of development opportunities, including to build careers and meaningful relationships, can put individuals at a disadvantage which is difficult to address later in life (McGorry & Mei, 2018). The stress-vulnerability model

(Zubin & Spring, 1977) posits that due to early experiences, genetics and a lack of protective factors, some individuals are less well equipped to manage stressful life events. This can help explain why individuals can find it difficult to break away from adversity, particularly when adversity has begun in early life.

There are many ways in which young people can be vulnerable to the development of mental health problems and other adversities in early life, including issues around housing, parental mental health, and access to financial resources. The Every Child Matters Green Paper (Department for Education and Skills, 2003), enforces the importance of family support, early intervention and high quality, effective services which work well together. Part of the rationale for services working together is to reduce the risk of serious incidents occurring as a result of young people's needs being missed. Since 2020, integrated care has gained more prominence in the NHS and Integrated Care Systems (ICS) are being implemented. This will involve multiple services across health and social care working together with the aim of improving efficiency and patient care (NHS, 2020). Intuitively, this approach makes sense. However, there is a need to review the evidence to explore the best approach to integrating mental health care with other services. The systematic review contained in this thesis portfolio will focus on examining the available evidence on the integration of social care and mental health care provision. The review will investigate the clinical and cost effectiveness and service user experience of integrated mental health and social care for young people. The research included in the systematic review chapter all took place prior to the COVID-19 pandemic, which has significantly impacted the lives of young people. The pandemic has resulted in huge changes to daily life worldwide (Baloch et al, 2020) and researchers and clinicians are particularly concerned about the impact for younger people (Young Minds, 2021). The pandemic has resulted in education provision moving online and disruption to workplaces, impacting young people's opportunities to socialise which is important in their development (Erikson, 1963). This may be the type of disruption which could lead to longer term impacts across the lifespan (McGorry & Mei, 2018). There is also a need for a deeper understanding of the views of young people with pre-existing mental health difficulties. Using a qualitative approach, the empirical paper in this portfolio aims to understand how young people with a history of mental health difficulties and low levels of structured activity have experienced the COVID19 pandemic and its restrictions.

This thesis utilises a mixed methods approach with a quantitative and qualitative systematic review and a qualitative empirical project underpinned by a critical realist perspective. Both papers are a part of larger projects which will support developing the evidence base more widely. The researcher joined the systematic review project at the full text screening stage to take on responsibility for one specific area of the project. With regards to the empirical paper, the researcher independently developed a protocol for a very similar project. Their supervisor was working with the DisCOVery team which was interested in the same topic area and suggested that the researcher joined this project to combine resources and avoid duplication.

Does integrated mental health and social care improve clinical effectiveness, service user experience and cost effectiveness of services: A Systematic Review.

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This paper has been prepared for submission to the Early Intervention in Psychiatry journal. Author guidelines can be found in Appendix A.

Chapter Two: Systematic Review

Does integrated mental health and social care improve clinical effectiveness, service user experience and cost effectiveness of services: A Systematic Review.

Abstract

Integrated care is increasingly being used in the NHS to support better care delivery but there is limited evidence around its clinical and cost effectiveness for young people with both mental health and social care needs. This systematic review aimed to identify the current evidence with regards to clinical effectiveness (assessed by accessibility of services, wait times, early detection, accessibility of treatments, clinical outcomes), cost effectiveness and service user experience of integrated social and mental health care services. Database and Google Scholar searches identified 12 studies which met the review criteria. Data were extracted and critically appraised. The quality of evidence was weak-moderate with mainly cohort studies and 11 studies were undertaken outside the UK. The review found evidence in support of integrated care in improving service-user experience, limited evidence to support clinical effectiveness, and no evidence to support cost effectiveness. With the exception of improved service-user experience, there is currently an absence of evidence for the wider benefits of integrated mental health and social care for young people. Recommendations are made for further research, specifically UK-based NHS research which the implementation of Integrated Care Services may provide opportunity for.

Key words: youth, integrated care, mental health, social care

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Introduction

Mental health difficulties are the highest cause of disability in young people up to age 25 across the world (Erskine et al, 2015). Youth is an important, yet challenging, developmental period, with 75% of mental health problems developing by age 24 (McGorry & Mei, 2018). Interruptions in this period can lead to significant impacts on identity, health, employment and relationships across the lifespan (Collishaw et al, 2004). To support early detection and intervention, specific services for individuals aged 12-25 are becoming more common globally and are also being implemented in some NHS teams, (McGorry et al, 2013, Wilson et al, 2018).

However even where specialist youth services exist, delivering services to this clinical population can be challenging. Young people often feel embarrassed about seeking help due to stigma (Gulliver et al, 2010). Many NHS services require a GP referral (Shaw et al, 2005), and young people are less likely to have a regular GP which creates an access barrier (Kang et al, 2020). Even following referral, services have specific criteria and young people can find that services are not available to meet their needs. Falling through the gaps of child and adult services is particularly common (Appleton, 2021). Waiting lists can also be lengthy and can increase feelings of hopelessness (Pugh, 2020). Young people, particularly those described as "hard to reach" such as care leavers, or those who are homeless, are at an increased risk of developing mental health difficulties (Brown et al, 2016). This group find it difficult to engage consistently or develop a trusting relationship with services (Lynch et al, 2021) and treatment drop-out rates are high (de Haan et al, 2018). The impact of mental health for young people and the burden on services have both increased since the onset of the COVID-19 pandemic (Fofana et al, 2020), and as such there is an urgent need to better support young people in a way that is effective and efficient.

In a healthcare context, integrated services can be defined by Gröne and Garcia-Barbero (2001) as "bringing together of inputs, delivery, management and organisation of services to improve access, quality, user satisfaction and efficiency of services". A systematic review by Baxter et al. (2018) found evidence that integrated GP and mental health services increase accessibility, patient satisfaction and the patient perception of care quality. For young people, research suggests that integrating mental health services with primary healthcare can reduce stigma and systemic barriers, as well as reducing difficulties in access for those in remote locations (Campo et al, 2015). However, there are challenges with providing services in this way. These may include unclear boundaries or understanding of job role, professionals lacking confidence or competence in areas they see as different to their core expertise and the logistical challenges of connecting health and social care provided and commissioned by different services (Servili et al, 2012). It is hypothesised that even if these services involve a higher cost initially, they are likely to reduce an individual's need for longer term support, suggesting wider cost efficiency (Cubillos et al, 2021). However, this is a complex area and evidence to support this assertion is currently lacking (Nolte, 2021). Despite these challenges and uncertainties, the NHS is committed to integrating services as part of its Long-Term Plan (NHS, 2019) and has recently developed Integrated Care Systems (ICS), allowing services in local areas to work together more efficiently, although these are in early stages of development (NHS, 2020).

Social care is one service which can be integrated with mental health care. Broadly, social care is defined as government services which are offered to disadvantaged or vulnerable people to support individuals to engage with society, access community provisions or live independently (Munday, 2003). However because the term is so broad across different populations it is recognised that social care is difficult to define (Long et al, 2002). Social care research aims to identify ways to improve individual's quality of life and maintain their dignity, independence, and ability to live well (NIHR, 2022).This may include interventions to identify appropriate housing or with job preparation. Maslow's Hierarchy of Needs theory (Maslow & Lewis, 1987) suggests that individuals are required to meet their needs in order of how closely related they are to survival. For example, individuals are unable to grow and develop if their safety needs, such as food and shelter are not met. Social care literature often makes use of this theory to describe both the importance of and the target of their interventions (Downes, 2018). Those with difficult life circumstances are more vulnerable to poor mental health, which can make it more difficult for individuals to make positive changes to improve their health and their life circumstances. This is commonly referred to as having complex needs (Rankin & Regan, 2004).

Practically, the services that social care provide adapt to mirror the changing needs of individuals throughout the lifespan. For young children, social care includes family support or providing residential or foster care, or support to access education (Ringel et al, 2018). For young adults, social care aims to support the transition to adulthood for young people who are vulnerable or disadvantaged, including offering support to access housing, healthcare, or employment (Settersten, 2008). A systematic review found high levels of mental health difficulties in young people who were homeless and describes how this creates a cycle which is difficult to break (Medlow et al, 2014). Social care may be the ideal place to improve identification of mental health need and increase access to mental health support, as specific services are required to engage young people with complex needs (Ryall et al, 2008).

Appropriate and timely intervention is important in supporting young people's mental health and to reduce the longer-term impact. It is possible that integrated social care and mental health services may support early diagnosis, better access to services and offering intervention. However, little is known about the research that has taken place to better understand effectiveness, efficiency and service user experience, which this review will explore.

This review aimed to answer the following research questions:

1. Does integrated mental health and social care improve the effectiveness of services for young people? (Measured by: access to services; access to treatment; reduction in service waiting times; improved early detection of mental health difficulties; improved clinical outcomes.)
2. Is integrated mental health and social care cost-effective?
3. Does integrated mental health and social care improve user experience of care?

Methods

This review specifically explored the integration of mental health services within social care. However, the searches were part of a wider project looking at the integration of a range of different services with mental healthcare. The protocol was registered on Prospero on 01/07/2020, Prospero ID: CRD42020185235.

Searches were completed on 5th December 2020 and updated in March 2022 using the following databases: MEDLINE – medical literature (OvidSP), EMBASE – Biomedical and Pharmacological database (OvidSP), PsycINFO – Behavioral Sciences and Mental Health (OvidSP), Child Development and Adolescent Studies (EBSCO), ERIC – Education Research Information Centre (EBSCO), ASSIA – Applied Social Science Index and Abstracts (ProQuest) and British Education Index (EBSCO). There were three search strands – integration, mental health and children/young people.

Inclusion criteria are shown below in Table 1.

Table 1: Inclusion Criteria

CRITERIA	SPECIFICATION
POPULATION	• Children and young people aged 0-25 years
INTERVENTION	• Integrated healthcare models
COMPARATOR	• If present, different service delivery model.
OUTCOMES	• Access to services • Waiting times • Early detection • Early access to treatment • Clinical outcomes (quality of life, function, reduced symptoms) • Cost-effectiveness • User experience
SETTING	• Any healthcare delivery setting
STUDY DESIGN	• Empirical studies (randomised/quasi randomised controlled trial, controlled before-and-after, cohort, cross sectional and qualitative studies)
COUNTRY	• High incomes countries
DATE	• Earliest available

Studies were excluded if they were not original research; were not focused on integrated healthcare of 0–25-year-olds; did not look at the outcomes being studied; were non-English. As these broader criteria referred to the larger review, two further inclusion criteria were later applied after initial searches for the research questions addressed by this paper:

- Papers with a youth population (average age of participants 16-25) as social care needs for young adults are different to those of young children
- Papers where the intervention specifically referred to social care or included a social care element. For young adults, social care aims to support the transition to adulthood and promote independence for those who are vulnerable or disadvantaged (Settersten, 2008), so interventions included those which supported areas such as including but not limited to, offering support to access housing, healthcare, or employment.

Supplementary searches included handsearching reference lists of identified articles and searching the first 100 records of Google Scholar.

Cadima was used to organize studies. Search results were merged and duplicate records removed. Two reviewers independently undertook study selection for inclusion in the systematic review and disagreements were resolved with a senior reviewer. Titles and abstracts were reviewed to remove visibly irrelevant studies. The full texts of remaining studies were then retrieved and studies were compared against inclusion/exclusion criteria. Lastly, studies were organized into the different categories of interest (school, physical health etc), of which social care was one.

The PRISMA diagram in Figure 1 below shows the studies identified.

Figure 1 PRISMA Diagram

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

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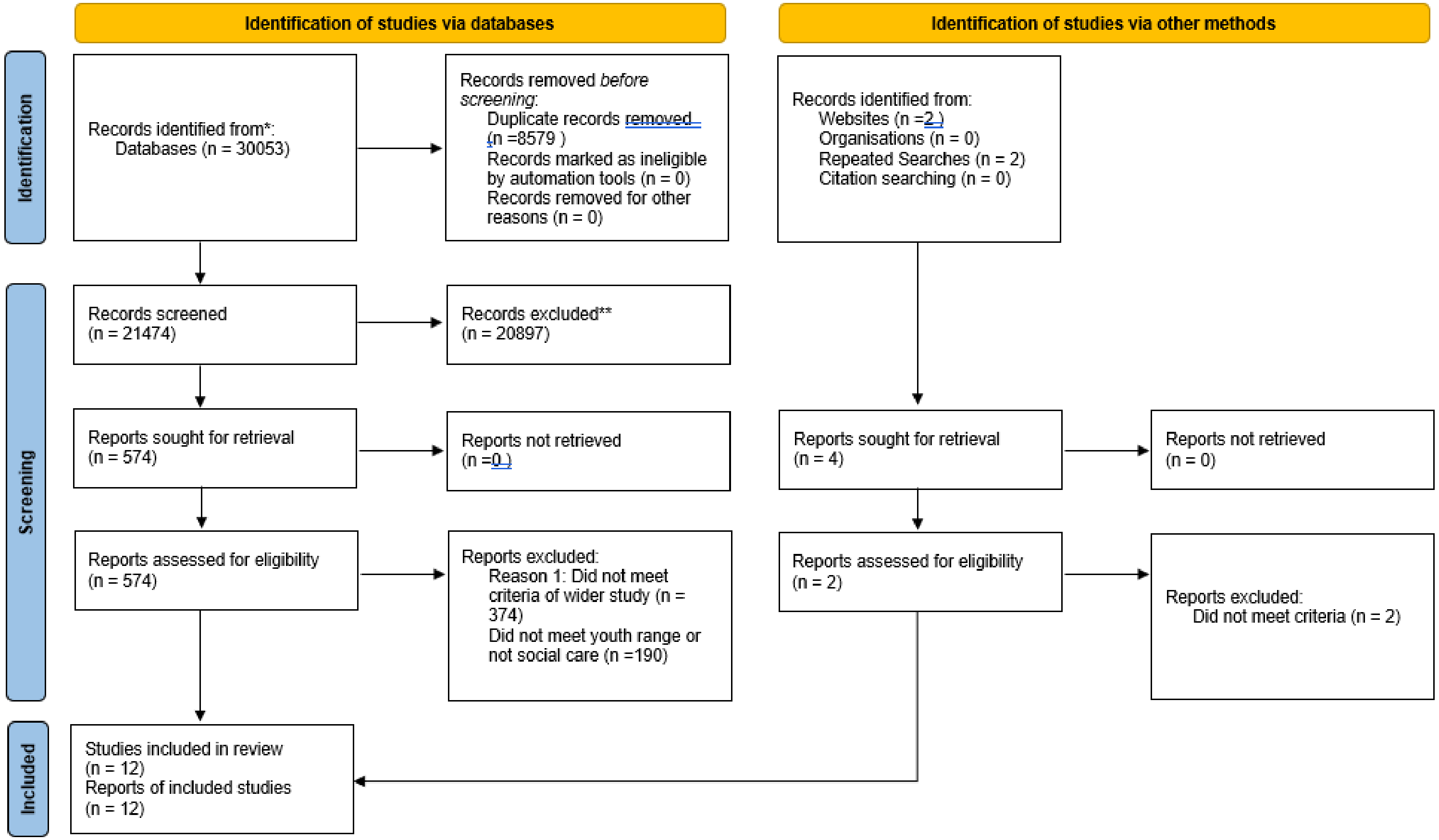

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Data from the identified studies including demographic details and information relevant to the research questions were extracted into an Excel spreadsheet to support synthesis. Where the papers did not address one of the research questions, this was also recorded. The extraction recorded specific measurements from the papers to support benefits of the interventions for each of the research questions. This consisted of any outcome measure or metric which compared either participant scores pre or post receiving the intervention or comparison between the intervention and another service which did not include integrated care. Where the papers lacked this, it was recorded that no evidence was found to answer that research question within that paper. However, where papers described interventions as improving these areas but provided no measurements to support this (for example, designing an intervention to increase accessibility but with no measurement which demonstrated that this had the intended impact) this was discussed to highlight an anticipated or possible benefit but where supportive evidence is lacking.

Quantitative studies were critically appraised using the Effective Public Health Project Practice (EPHPP) Quality Assessment Tool for Quantitative Studies, as this is specifically designed for healthcare research (Effective Public Healthcare Panacea Project, 2022). A weak rating in one are suggests moderate evidence, more than one weak rating suggests weak evidence. This could not be used for qualitative studies, so the CASP qualitative checklist was used for two qualitative studies, and the qualitative component for one study. A senior reviewer co-rated 10% of papers for both data extraction and critical appraisal to ensure agreement within the study team and increase confidence in the findings of the review.

Results

The searches returned a total of 21474 records with 71 relevant to social care. After applying inclusion and exclusion criteria, 10 eligible studies were identified. Repeating the searches, running an amended version of searches using Google Scholar and hand searching references lists led to identifying a further two papers, leaving a total of 12 papers to review. The papers had a combined total of 3133 participants including 120 professionals, 13 parents and 3000 youth participants (mean age 20.5 years). There were 27.53% male participants, likely because two larger studies were aimed at pregnant/parenting adolescents and the sample was entirely female.

Study Characteristics are shown in Table 2.

Table 2: Study Characteristics

Author, Year	Country	Study Design	Clinical population	Sample size	Mean age	% Male	Intervention, length of time	Means of Integration	Outcome measures	Quality
Hagner et al, 1999	USA	Cohort - one group pre and post	Young people with emotional difficulties finding adulthood transition challenging	18	18.92	61.11	Two year intervention consisted of future planning, flexible high school, employment support, interagency collaboration, mentoring, social skill building and resources.	All interventions delivered by the same team with signposting / interagency support where required	Questionnaire measuring satisfaction. Changes in employment, education status, involvement with the police. Interviews.	Moderate
Dore-Gauthier et al, 2020	Canada	Cohort- two groups pre and post intervention	Youth experiencing homelessness, first episode psychosis and substance use	24 intervention, 26 historic control (Early Intervention in Psychosis support alone)	23.84	92	Two year intervention. Focuses on housing support and signposting. High intensity and flexible follow-up during critical periods. Psychosis interventions include psychosocial interventions, case management, family interventions, CBT, supported employment program, group therapies.	All interventions delivered by the same team with signposting / interagency support where required	Interviews and medical notes reviews. Housing stability = where participant lived in last three months and where they wish to stay. Antipsychotic treatment, mental health services use, SOFAS, GAF, CGI-S AUDIT / DUDIT, DSM-4 Diagnosis collected via estimates of clinical record.	Moderate
Harris et al, 2003	USA	Cohort - one group pre and post intervention, analysis of records	Young people with unstable housing and with a diagnosis or at risk of HIV.	1426	21.2	35.9	Outreach, mental health counselling, HIV testing, case management services. Average length of intervention not reported.	All interventions delivered by the same team with signposting / interagency support where required	Service contact / case management engagement in psychosocial treatment; emergency medical care.	Moderate

Author, Year	Country	Study Design	Clinical population	Sample size	Mean age	% Male	Intervention, length of time	Means of Integration	Outcome measures	Quality
Kidd et al, 2019	Canada	Cohort - one group pre and post, quantitative and qualitative	Youth with past experiences of homelessness	31	21.06	41.95	Collaborative housing outreach programme. Outreach based case management, group and individual mental health supports and peer support. Average length of intervention was 18 months.	All interventions delivered by the same team with signposting / interagency support where required	Qualitative interviews Community Integration Scale, brief World Health Organization Quality of Life Scale (WHOQOL-BREF) Mental Health Continuum-Short Form, 25-item Conner-Davidson Resilience Scale, Mindful Attention Awareness Scale (MAAS), MOS Social Support Survey.	Quantitative : Moderate; Qualitative: Valuable to support the quantitative study
Vorhies et al, 2009	USA	Cohort - one group pre and post	Young parents with severe mental illness in a residential unit requiring support to transition into independent living	25	18.59	0	Drop-in centre and supported living. 24-hour staff support, employment and education services, therapy, Therapeutic nursery with medical care, case management, child development classes, parent coaching, and Theraplay. Average length of intervention not reported.	All interventions delivered by the same team with signposting / interagency support where required	Brief Symptom Inventory (BSI), Child Abuse Potential Inventory (CAP), Parent Opinion Questionnaire (POQ), Parenting Stress Index (PSI), Behaviour Status Changes.	Moderate
Busen et al., 2007	USA	Cohort - one group pre and post intervention, analysis of records	Young people experiencing homelessness	95	20.5	46.32	Medical mobile unit provided medical and mental healthcare services delivered by an MDT aiming to reduce health risk behaviours. Average length of intervention was 14 months.	All interventions delivered by the same team with signposting / interagency support where required	Changes in risk indicators: immunizations, adherence to psychological/ substance misuse and medical treatment, reduction in substance use and responsible sexual behaviour	Weak

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Author, Year	Country	Study Design	Clinical population	Sample size	Mean age	% Male	Intervention, length of time	Means of Integration	Outcome measures	Quality
Powell et al., 2016	USA	Cohort- one group pre and post	LGBTQ young people experiencing homelessness	210	19.7	44.8	"One stop shop" - signposting, substance use interventions, Motivational Enhancement CBT, intensive case management, support with housing, sexual health sessions and around HIV. The intervention was offered for six months but this could be extended by another six months.	All interventions delivered by the same team with signposting / interagency support where required	Global Assessment of Individual Needs (GAIN), Client Outcome Measures for Discretionary Programs Government Performance and Results Act (GPRA) Tool	Moderate
Van den Steene et al., 2019	Belgium	Qualitative interviews	Young females with mental health difficulties and a complex / unsafe family environment	Nine adolescent girls, 12 parents. 44 professionals	16.8	0	Collaboration with goal setting, evaluations and decisions with joint responsibility. Child welfare team also provided practical, safety and social support; pharmacological treatment from child and adolescent psychiatry. Average intervention length was 2 years	Input provided jointly by Child Welfare and Child and adolescent psychiatry.	Qualitative - In-depth interviews with adolescents, perspectives of professionals were collected in focus groups	Valuable to understand the viewpoint of service users
Slesnick & Erdem, 2012	USA	Cohort - one group pre and post	Young homeless parents	15	25.2	0	Housing support - three months financial assistance, six months of case management services and an evidence-based substance abuse treatment (Community Reinforcement Approach; CRA). Intervention length was 6 months	Interventions all provided by one practitioner	Demographic Computerized Diagnostic Interview Schedule; Form 90 drug and alcohol interview plus urinalysis; Short-Form-36v2 (SF-36v2) Child Behaviour Checklist; Parenting Stress Index Short Form (PSI/SF); Women's Experience with Battering Scale	Moderate

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Author, Year	Country	Study Design	Clinical population	Sample size	Mean age	% Male	Intervention, length of time	Means of Integration	Outcome measures	Quality
Ashby et al., 2019	USA	Cohort- two groups pre and post intervention	Pregnant and parenting adolescent girls accessing care from a obstetric and paediatric medical home	429 in pre-intervention group (enrolled in program before trauma informed principles implemented), 415 intervention group	18.65	0	Behavioural health integrated into the medical centre. Consisted of consultation, therapy and medication management using a trauma informed approach. Average length of intervention not reported.	The implementation of trauma informed principles at the medical centre	Retrospective medical records reviews. Interviews Centre for Epidemiologic Studies Depression Scale (CES-D) Population demographics psychosocial variables, clinical birth data.	Moderate
Henderson et al., 2021	Canada	discrete choice experiment (DCE) survey	Young people with mental health difficulties	274	22.64	38.5	Not applicable	Defines integrated services as services which reduce barriers to better support vulnerable youth	DCE (split into three classes according to answers) and Global Appraisal of Individual Needs - Short Screener (GAIN-SS)41	Moderate
Farr et al, 2021	UK	Qualitative interviews	Professionals working on i-Thrive model	76 professionals, 3 service users, 1 parent	Not provided	Not provided	Strengths based model allowing young people to access mental health and crisis support. This included psychological and pharmacological treatments including welfare and housing. Case management support provided where required. Average length of intervention not reported.	Both mental health and social care practitioners following the same national protocol and sharing information and decision making at all levels of need.	Qualitative interviews to explore participant (professionals and service user / parent) views	Valuable as a UK study though struggles to summarise service user and clinician perspectives

Nine studies were cohort studies measuring differences before and after an intervention. Two of these compared two groups before and after intervention, in both cases the comparator was a similar earlier intervention without an integrated component. The remaining studies had no comparator. Seven studies involved direct participant research and two used clinical records only. The remaining studies were two qualitative papers and one discreet choice experiment survey, using matrices to understand participant's priorities regarding integrated mental health and social care services.

The interventions evaluated varied but included elements of case management, psychological therapy, pharmacological intervention and a range of social care support such as housing, career interventions, family support and youth pregnancy, as well as signposting. Interventions were integrated either by the same team providing all interventions or a partnership between two specific services.

The studies were undertaken in four different countries; USA, Canada, Belgium and the UK. Though participants were mainly young people, two studies also included family members and professionals in the sample. All young people included had reported mental health difficulties and at least one recognised social care issue including homeless, pregnant or young parents, transitioning to employment or a complex family environment. One study looked to evaluate a programme supporting any social care need alongside any mental health need, and the final study looked to identify what young people valued from integrated mental health and social care. There were no commonalities with regards to specific outcome measures.

Appraisal

Overall, the studies provide a weak to moderate quality of evidence, as assessed by the EPHPP and CASP Qualitative Checklist. There are no randomised controlled trials (RCTs).

RCTs have been understood to be the gold standard in research, however clinical services like these are more complex than RCTs will allow (Grossman & Mackenzie, 2005). There are two studies which compare integrated and non-integrated care which can more clearly show the impact of integrated care, though these do not receive higher quality ratings. A factor which may impact the quality of the results is the large number of outcomes recorded, suggesting a risk of type 1 error of finding a significant result by chance. Qualitative studies are well utilised to provide a service user perspective.

Results

There was no exploration of cost effectiveness or waiting times. The other research questions are shown in Table 3 below.

Table 3: Study results

Author, Year	Access to Services	Detection	Access Treatment	Clinical Outcome	Service User Experience
Hagner et al, 1999	-	-	-	-	✓
Dore-Gauthier et al, 2020	-	-	-	✓	-
Harris et al, 2003	-	-	-	✓	-
Kidd et al, 2019	-	-	✓	✓	✓
Vorhies et al, 2009	-	-	-	✓	-
Busen et al., 2007	-	-	✓	-	-
Powell et al., 2016	-	-	-	✓	-
Van den Steene et al., 2019	-	-	-	-	✓
Slesnick & Erdem, 2012	-	-	-	✓	-
Ashby et al., 2019	-	✓	-	✓	-
Henderson et al., 2021	-	-	-	-	✓
Farr et al, 2021	-	-	-	-	✓

Key: Found evidence of improvement=✓ Did not improve=X Did not measure=-

Access to services:

None of the studies measure the impact of integrated care on service access. Many of the integrated interventions were designed to increase accessibility for hard-to-reach groups. Examples include a drop-in centre (Vorhies et al, 2009), and a medical mobile unit (Dore-Gauthier et al, 2020). However there is no data to evidence how accessible the services were. Only one qualitative study considered the impact of accessibility (Farr, 2021). Healthcare staff participants felt that the integration increased accessibility to services through using a needs-based approach, providing flexibility in re-referrals, increased information sharing to other services and signposting as well as collaborative decisions between services about risk and ending treatment. However, they do not explain how these factors increase accessibility and there is no quantitative data to support these views. As access to services was not formally measured, there is an absence of evidence that integrated care supports accessing services.

Access to treatment

Two studies reported an increase in participants accessing treatments. Kidd et al (2019) reported that participants accessed further treatment including CBT and substance detox. Busen et al (2007) report that accessing treatment was a successful outcome and many participants accessed medical or psychological intervention. However, only descriptive statistics are provided and studies had small samples so it is not possible to state whether these gains are significant, or whether it was the integrated aspect of the intervention which led to this outcome. Four studies (Powell et al., 2016; Vorhies et al, 2009; Dore-Gauthier et al, 2020; Hagner et al, 1999) describe an aim of the intervention was to increase access to treatments but this was not measured. Overall, this appears to suggest that easier access to treatment is an aim of integrated care but because of the way the data were collected there is insufficient evidence that that integrated care leads to improvements in treatment access.

Early detection

Whilst the studies are all aiming for early intervention in the life course, there is little mention of finding problems early and participants generally have existing complex needs. However, there were exceptions. The Ashby et al study (2019) provided an opportunity for adolescents accessing support with pregnancy and parenting to be assessed and access treatment for trauma. Of these young people, 29% described a traumatic history for the first time, allowing services to intervene at an earlier point and before symptoms became worse resulting in an increased likelihood of needing more intensive treatment. Other studies, such as the Dore-Gauthier (2020) study did not formally measure detection but authors believed that the outreach approach and strong partnerships with different organisations allowed them to detect twice as many homeless young people with psychosis requiring support and was a significant factor in the clinical improvements they noticed. One aim of the Harris et al (2003) study was to increase early detection for HIV, but there is no data provided as to whether this outcome was met. These examples suggest there may be elements of integrated care which support increased early detection of mental health or social difficulty; however these studies overall do not provide enough evidence to suggest that this is a particular benefit of integrated care.

Clinical outcomes

There was a range of mental health and social care outcomes in eight of the studies as summarised below.

Mental health symptoms: Two studies reported improvements in mental health symptoms. Powell et al (2016) reported a significant improvement in three of ten areas of mental health symptoms as assessed by the GAIN (Global Appraisal of Individual Needs) comparing before and after intervention scores. These improvements were in domains of reduction in serious anxiety or tension, days disturbed by emotional problems and days disturbed by traumatic memories. Slesnick & Erdem (2012) report that participant's general mental health improved significantly following the intervention as evidenced by improvements in composite SF-36v2 (Short Form Health Survey version-2.0) scores – BDI (Beck Depression Inventory) scores also reduced but did not meet significance threshold. Dore-Gauthier et al (2020) reported a significant difference in days spent in hospital between the intervention participants and those receiving treatment as usual. Their study also reported significant increases in scores on the GAS (Global Assessment of Symptoms), GAF (Global Assessment of Functioning) and SOFAS (Social and Occupational Functioning Assessment Score) before and after treatment but no difference in scores between the intervention group and treatment as usual. This suggests that interventions lead to improvements but this is not necessarily due to the integrated care element. Vorhies et al (2009) reported no significant improvement in mental health symptoms measured on the BSI (Brief Symptom Inventory), which may be due to using a different measure. The other five intervention studies did not directly measure mental health symptoms. This provides some evidence of integrated care interventions ability to reduce mental health symptoms.

Substance misuse: Two studies interventions provided support for substance misuse. Dore-Gauthier et al (2020) did not find significant differences between the intervention and non-intervention group with regards to substance misuse as assessed by AUDIT and DUDIT (Alcohol/Drug Use Identification Test); however, substance misuse was higher in participants receiving the integrated intervention at baseline, suggesting that integrated intervention was more effective as at follow-up, rates between the groups were similar. They also reported one type of substance abuse had increased significantly in the treatment as usual group. Slesnick & Erdem (2012) reported that days with substances had reduced significantly at three month follow up, though this had increased at 6-month follow-up, measured using both Form 90 calendar data and urine screening. This provides some evidence that integrated care supports reduction in substance misuse where this is a focus of the intervention.

Employment/education: Six studies explored employment and education outcomes. In three studies, descriptive statistics post intervention were provided rather than analysis of changes pre/post or between interventions (Hagner et al, (1999); Vorhies et al, (2009); Kidd et al, 2019)). This makes it difficult to ascertain the impact of the intervention on employment and education outcomes. However, three studies did provide such comparisons. Slesnick & Erdem (2012) reported no significant difference in employment rates pre and post intervention. Powell et al., (2016) reported a significant increase in participant's engagement in full time employment but did not find significant increases in participants engaging in education. Dore-Gauthier et al (2020) reported no significant difference between integrated intervention and treatment as usual group in employment and education rates post intervention, and these rates remained low in both groups. These results do not provide evidence that integrated care improves employment and education.

Housing/homelessness: Three papers investigated housing as an outcome. Slesnick & Erdem (2012) reported a significant reduction in days spent homeless in the last three months both at three month and six month follow up. Powell et al., (2016) reported significant reductions in homelessness in last 90 days, days homeless in last 90 days and participants reporting housing stress. Dore-Gauthier et al, (2020) did not find significant differences in reported lengths of time to achieve stable housing between the intervention and treatment as usual participants but both showed gains. This suggests that integrated care can support participants to attain stable housing; but it is not necessarily superior to standard care.

Parenting/pregnancy: Three studies aimed to provide integrated mental health and parenting / pregnancy interventions. Vorhies et al, (2009) did not report differences in parenting stress scores on the CAP but did report significant reductions in two of the six subscales of parenting stress on the POQ measure (family responsibility and care and proper behaviour and feelings) suggesting lower parental expectations. Slesnick & Erdem (2012) reported significant improvements in externalising and internalising behaviour in participant's young children rated using the Child Behaviour checklist, but no difference in parenting stress levels measured by PSI/SF (Parental Stress Index Short Form). Ashby et al., (2019) reported the intervention group had significantly higher rates of attendance at prenatal appointments and lower rates of low birthweight babies. Though this evidence is varied and limited, it suggests some support for improved outcomes for infants following integrated intervention delivered to the mother. No interventions were directed at fathers.

The range of mental health and social care outcomes described demonstrates that there are many ways in which integrated care can be beneficial, depending on the target outcome. However, there is not strong and consistent evidence for any particular clinical outcome, and due to study design it is difficult to ascertain whether improvements can be attributed to the integrated nature of the intervention.

Service-user perspective

Five studies investigated the service user perspective of receiving integrated social and mental health care. Three utilised a qualitative methodology to evaluate specific interventions; one utilised a discreet experiment survey which sought to understand what participants value about integrated care; one used qualitative data on satisfaction of outcomes. Participants felt that integrated care was flexible and tailored to their needs (Kidd et al, 2019; Henderson et al., 2021; Van Den Steene et al, 2019); had different elements through one access route (Kidd et al, 2019; Henderson et al., 2021) was delivered efficiently (Kidd et al, 2019; Henderson et al., 2021) balanced intervention and independence (Kidd et al, 2019); enabled easier access to treatment (Van Den Steene et al, 2019); focused on society integration (Van den Steene et al., 2019) and allowed shared decision making (Farr et al, 2021, Henderson et al, 2021). Henderson et al's research also suggested that participants preferred integrated care which prioritised diversity and trauma informed principles. Farr et al (2021) suggested participants found the time limited aspect of integrated care unhelpful, however this maybe due to differing experiences of iThrive intervention rather than specific to integrated care more generally as this finding was not replicated by other studies. Hagner et al (1999) identified statistically significant increases in satisfaction with work, school, progress toward goals and with handling problems using their own questionnaire. This suggests that participants valued and perceived multiple benefits of integrated care and the evaluative studies suggest participants had largely positive experiences as compared to non-integrated care, providing evidence that integrated services may improves service-user experience.

Discussion

This review identified 12 studies which met the inclusion criteria and answered at least one of the research questions. The evidence reviewed provides a good overview of the many ways in which social care and mental health provision can be integrated. The strongest supportive evidence of integrated care was with regards to the service user perspective. Limited evidence was identified with regards to effectiveness, measured by clinical outcomes, early detection, waiting lists and improved access to services and treatment. However, this was largely due to study design and variation in how these outcomes were assessed rather than null findings. No evidence was identified to support cost effectiveness, again due to this not being formally measured by studies.

The strongest evidence to support integrated care appeared to be improved service-user experience. Participants identified many aspects about integrated care that they felt were beneficial compared to experiences and expectations of standalone care, including flexibility and specific to need. These are themes identified previously as important for young people accessing services (Macdonald et al, 2021), often a difficult process at an already distressing time (Salaheddin & Mason, 2016). This research supports integrated care as a way of improving this experience.

The evidence for improved clinical outcomes from the identified studies was inconsistent. Although many of the studies reported improvements in some areas, only two of the 12 studies compared integrated care with non-integrated care, providing limited evidence that integrated care is superior to standalone care. There were also many elements of the research which did not report improvements and many different outcomes, suggesting that positive results may be due to chance, known as a type 1 error (Mayo & Spanos, 2011). Regarding the other aspects of effectiveness, with a few exceptions, studies did not explicitly measure accessibility to services and treatments or the impact on waiting lists, or early detection. This may be because almost all studies took place outside the UK and access issues may be very different. Generally, access in the UK is through the GP, and referrals within the NHS, which is different to other healthcare systems (Shaw et al, 2005). Many studies commented on accessing "hard-to-reach" groups, and this was the focus rather than detecting additional problems early. Increased accessibility is considered an important benefit of integrated care (Baxter et al, 2018). The NHS Long Term Plan (NHS, 2019), which prioritises the implementation of Integrated Care Systems (ICS), focuses on the benefits of the sustainability of the NHS and allowing departments to work more efficiently, rather than its ability to improve clinical outcomes. The current evidence is therefore lacking that integrated care improves clinical outcomes.

Analysis of cost effectiveness is absent from the studies, although a small number of the studies state that consideration of costs is important. Cost has a huge impact on the way services are commissioned in the NHS (NHS Long Term Plan, 2019). It may be that these pressures are felt differently in countries with different healthcare systems; however, the lack of cost reporting limits the usefulness of these articles as it is not possible to understand efficiency of this way of working. Cost effectiveness may be difficult to evidence due to the interventions being based on clinical need rather than standardised plans and the scope of costs and savings (Nolte, 2021). However, understanding cost effectiveness is essential for the NHS to provide the best care as efficiently as possible which are key priorities (NHS Long Term Plan, 2019). Full costs, including the cost of the intervention and the costs and savings to services, wider society and the individual, would allow comparison for the efficiency of integrated care as compared to other interventions.

This review was undertaken to identify how useful integrated health and social care may be for young people accessing NHS services in the UK. As only one paper contains data from NHS services, there is less applicability from the majority of the studies in this review. However, it remains important to position the review in the context of identifying the available evidence as it applies to the NHS.

Research Implications

This review suggests multiple ways in which research could better evidence the value of integrated care for young people with mental health and social care needs.

Future research could prioritise the different potential benefits of integrated care which are important to the NHS – impact on waiting lists, accessibility of services and treatment and early detection as well as cost effectiveness, which these studies do not assess. NHS services have invested in integrated care services and this may provide opportunities for targeted research and service evaluations. In addition, using standardised outcome measures would better demonstrate clinical change and impact on service user and healthcare relationships, though this is challenging due to the varied nature of interventions and the primary targets. Mental health measures may include the Patient Health Questionnaire 9 (measure of depressive symptoms) or the Generalised Anxiety Disorder 7 (measure of anxiety symptoms) as these are commonly used in NHS services (Blenkiron & Goldsmith, 2019). Although RCTs are not feasible, comparison interventions are required to ascertain if integrated care is superior to other service delivery models. This could be achieved by using a non-integrated intervention in a comparable population either at a different time point (i.e. comparing current and historical data), as used in two studies here, or in a different geographical location. Investigating different approaches to integrating care (e.g. co-located services vs. partnerships between services) may also be useful. Finally, many of the studies reported that the interventions supported developing trusting relationships with young people described as ‘hard to reach’ who often find this difficult. A non-judgmental, trusting relationship has been shown to be the most important factor for young people accessing services and is an important factor in achieving positive outcomes (Lynch et al, 2021, Goicolea et al, 2018). Many studies comment on this but do not measure explicitly; future research could explore whether this is a benefit of integrated care.

COVID-19 has significantly impacted the delivery of services (Huang & Ougrin, 2021) and research also needs to identify how integrated care has changed, and what may be feasible or helpful now.

Clinical Implications

This paper identified an absence of current evidence to support implementation of ICS, which are currently being developed in NHS services. The NHS generally consists of practice which is evidence-based; however it is recognised that this is not always possible due to gaps in knowledge and the time it takes to complete research (Upton, 1999). Implementation of ICS and its evaluation may therefore support developing practice based evidence. A further implication from this review is that social care can encompass many areas (Long et al, 2002) and ICS teams will need to consider how they define social care and what services this involves in their integrated interventions.

Strengths and Limitations of Review

This review is the first of its kind known to the authors which explicitly explores the integration of social care with mental health care for young people. It utilised a thorough search strategy, providing a good overview of the varied ways in which social and mental health care might be integrated and explores a range of outcomes. As part of a wider review about integrated care for young people, this study contributes to the development of a wider understanding of the benefits this way of working.

However, there are a number of limitations which need to be considered. Social care is a wide-ranging topic and is understood to be a complex subject for a systematic review as it is a vast topic area with a lack of clear definition (Long et al, 2002). There may have been papers which were not identified in searches, or other researchers may have selected papers differently based on what their implicit of social care may involve. Another approach may have involved defining specific areas of social care, and using those as search terms – for example, housing or employment, in addition to social care. However, this would still have open to bias.

As a result of social care including diverse populations, the participants described in this study and the studies themselves have high levels of heterogeneity. This is likely because of the broad range that social care can cover. However, this means it is harder to draw meaningful conclusions as the data is so diverse and what applies to one population may not apply to another. More focused research on specific populations may help to address this.

As well as this, COVID-19 has significantly changed the way in which many health services are delivered, and this may impact the costs and benefits of integrated care. In order to encompass the breadth of integrated services, the review asked a number of questions, many of which the studies identified were unable to answer, and which made integrating varied study findings challenging. However, it provides several key recommendations for future research in this area, which is particularly timely given the recent UK investment in integrated care systems.

Conclusions

This review identified and synthesised 12 papers relevant to integrated social care and mental health. Evidence was inconsistent regarding effectiveness of interventions and there was no evidence to support cost efficiency, but the results do provide support for the role of integrated care in improving service user experience. Recommendations are made for more UK, NHS based research which can specifically investigate the costs and benefits of this way of working within the NHS. The development of ICS currently being implemented may provide opportunities for research and service evaluations to develop the evidence base.

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Chapter Three: Bridging Chapter

The aim of this chapter is to summarise the results of the preceding systematic review and outline the rationale for the empirical paper, including background for the PRODIGY study and DisCOVery study which influenced the empirical paper.

Systematic Review Results

The systematic review was part of a wider review to understand the value of integrated care for children and young people aged 0-25. The specific review described in the previous chapter focussed on integrated mental health and social care for young people aged 16-25. Through searches, the review identified 12 studies of relevance to clinical effectiveness and service user experience of these services. The results suggested that integrated mental health and social care improves service user experience. There was limited evidence to support integrated care in improving effectiveness of care and no measurement of the ability of integrated care to support cost efficiency. However, in many cases this was due to methodological limitations and variations in outcomes assessed – an absence of evidence rather than evidence suggesting that these services were not effective. Suggestions are made for further research, specifically NHS research as only one study took place in the UK and other healthcare systems globally are hugely different.

All of the research included in the systematic review took place prior to the COVID-19 pandemic. Research is also needed to understand what support young people with complex and pre-existing mental health needs might require following their experiences of the COVID-19 pandemic. The empirical paper aimed to understand more about the impact of COVID-19 on this group.

Background to Empirical Paper:

There are two research studies which are relevant to the empirical paper. These are PRODIGY and DisCOVery, which are discussed below.

Background to PRODIGY study:

PRODIGY (Prevention and treatment of long-term social disability amongst young people with emerging severe mental illness: A randomised controlled trial, Berry et al, 2022) was a randomised control trial with 260 participants across Norfolk, Sussex and Manchester. The research explored the efficacy of Social Recovery Therapy (SRT), a modified version of Cognitive Behavioural Therapy for young people with a range of severe and enduring mental health difficulties social disability (defined as engaging in less than 30 hours a week of work, voluntary work, education, leisure, housework or childcare (Berry et al, 2022). The project aimed to engage young people using an assertive outreach model like many of the studies in the review, with a view to increasing their level of structured activity. Part of the rationale for the research was that many psychological treatments focus more on treating symptoms instead of social recovery, which may not be sufficient in supporting genuine recovery in clinical populations where symptoms are preventing engaging with structured activity. The study also recognised that many young people who may benefit from treatment may find accessing services difficult, and an assertive outreach approach was used throughout the baseline and follow up assessments, as well as throughout the therapy, meeting participants in the community and their own homes rather than just in clinics, according to their preferences. The empirical study outlined in the next chapter recruited participants who had previously participated in the PRODIGY trial to explore their experiences of the COVID-19 pandemic. This sample was chosen because they were known to have complex mental health difficulties which predated the COVID-19 pandemic. This is in contrast to other studies exploring the impact of COVID-19 on the mental health of young people from non-clinical populations.

The SRT intervention outcomes from PRODIGY have been reported elsewhere and the trial element was not the focus of the current study.

DisCOVery

Recovery alongside social isolation: Research into the mental health impacts of COVID-19 for young people (DisCOVery) was funded by the National Institute for Health Research Applied Research Collaboration (ARC) for Kent, Surrey and Sussex. The study aimed to understand the impact of COVID-19 on young people, aged 16-35, living in rural and coastal communities and people accessing health, community or social support services before the pandemic. The study aimed to understand experiences and learn if COVID-19 has had an impact of greater severity, or if there have been strengths or helpful coping strategies which may have supported these individuals to manage.

There were two recruitment streams:

1. Young people were recruited through a range of social and healthcare services in Sussex and Norfolk
2. Former PRODIGY participants who consented to be contacted about additional research opportunities

The study utilised a mixed methods design to gain both quantitative and qualitative data. The results are currently being collated. The study reported in the next chapter focuses on qualitative data from former PRODIGY participants, so those who were not recruited via services.

Empirical project

The paper which follows presents the analysis of the qualitative interviews of the former PRODIGY participants regarding their experiences of the COVID-19 pandemic. This group was chosen for the sub-analysis because they were recruited outside of services and can all be understood to have a history of severe mental health difficulty and lack of structured activity.

The qualitative interviews are the focus of this paper and a small amount of quantitative data is presented to provide context for the sample. The interviews took place between March and June 2021, during which time restrictions changed significantly and vaccines were offered to the general public. Following the empirical paper, an additional chapter is provided which provides greater insight into aspects of the methodology and the analysis.

This project will contribute to the literature by adding the views and perspectives of a clinical population who are harder to involve with research due to lack of formal engagement with services.

The experiences of young adults with pre-existing mental health difficulties of living through the COVID-19 pandemic: A qualitative study

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Chapter Four: Empirical Paper

The experiences of young adults with pre-existing mental health difficulties of living through the COVID-19 pandemic: A qualitative study

Abstract:

The restrictions imposed by the COVID-19 pandemic have had significant and wide-ranging impacts on young people due to social isolation, disruption to education and employment opportunities, and young people with pre-existing mental health difficulties may be disproportionality affected. This research aimed to better understand the experiences of this group using a qualitative approach. Thirteen participants with mental health difficulties pre-dating the pandemic were interviewed between March and June 2021 using a semi-structured interview. Data were analysed using thematic analysis. The results indicated a reciprocal relationship between participants' mental health and their response to the pandemic. Main themes identified were how participant's mental health impacted their response to the pandemic (subthemes consisted of demonstrating established ways of coping; feeling less impacted than others; activating stress response) and how the pandemic impacted participant's mental health (with the subthemes of meaningful change; impacting recovery from mental health difficulties; previous beliefs). Approaching vs avoiding was used to capture how participants responded to the challenges and opportunities they experienced. There were many ways in which both their mental health and the pandemic made participant's lives more difficult, including the pandemic interfering with or preventing progress, reinforcing negative or hopeless beliefs and activating stress responses. However, participant's prior experiences supported them to utilise positive coping skills and some were able to make meaningful changes as a result of the pandemic. Recommendations are made for clinical practice and further research.

Keywords: COVID19, youth mental health, coping, avoidance, depression, anxiety, social

Practitioner points

Young people's pre-existing mental health difficulties impacted their responses to the pandemic, and the pandemic further impacted their mental health.

Participant's tendency to avoid or approach challenges influenced how they responded and although many participants found their circumstances extremely difficult to manage, others were able to utilise positive coping skills and make meaningful changes,

Services can support young people by using a strengths-based approach to help build coping skills, provide psychoeducation around resilience, support to develop goals and promote and build on positive change.

Introduction

The COVID-19 global pandemic has had significant impacts across the world (WHO, 2020). To date, there have been in excess of 504 million cases and 6.2 million deaths worldwide (World in Data, 2022). There are significant health, social and economic impacts not only of the disease itself but also the resulting restrictions and lockdowns (Douglas et al, 2020). Mental health has been severely affected, with increased levels of depression and suicidality reported across the population (O'Connor et al, 2021). As such, research in this area is of high priority, with over 200 longitudinal studies currently reported (Covid Minds, 2022).

Youth is a known to be a time of transition and a time for the peak onset of many mental health difficulties. Indeed, 75% of mental health problem develop by age 24 (McGorry &

Mei, 2018). This life stage is an important time for young adults as they begin building their identity, careers and relationships, and interruptions at this time can have long-term negative impacts on their mental health and overall functioning (Collishaw et al, 2004). Research suggests that the mental health impact of pandemics can be severe and long-lasting, with children and young people at a higher risk of depression and anxiety for up to nine years afterwards due to the impact of isolation (Loades et al, 2020). This group is therefore not only more at risk of interruption due to the pandemic, this interruption is also likely to have greater consequences than for other populations (Loades et al, 2020). Young people in employment are at early stages of building their careers and are more likely to be in unstable jobs, zero hours contracts, or negatively impacted by working from home. At different times during the pandemic, teaching at schools, colleges and universities has been remote, rather than in person meaning that they have missed out on important social interaction and friendships (Young Minds, 2021). Socially, young people are developing their identity and so are more reliant on friends who they may not live with and thus the effects of isolation are likely to be magnified (Levita et al, 2020).

A recent systematic review found 97% of students in the UK aged 18-25 reported at least one mental health concern following the pandemic, leading the authors to conclude that lockdown has caused a mental health crisis in young people (Owens et al, 2022). The Young Minds charity (2021) completed four surveys between March 2020 and January 2021 with young people with a history of mental health needs. They reported 69% of young people have struggled to cope with going back to school and 67% of participants felt that the pandemic would have long term impacts on their mental health. Conversely, one-third of young people surveyed by Soneson et al (2022) reported an improvement in their mental health during lockdown, experiencing less loneliness and benefitting from increased sleep and exercise. This suggests that the pandemic and its impacts have affected young people differently, and understanding why this is may help support young people who have found this period more challenging. It also provides some evidence that the pandemic may not have been as damaging to some young people, though these responses may have changed over time.

Though significant research is taking place, it is often quantitative in nature and aimed at general population samples. Research on the experiences of the pandemic for young people with pre-existing mental health difficulties is more limited. Early research suggests that as well as young people, those with pre-existing mental health difficulties and those from lower socioeconomic backgrounds are more likely to experience mental health difficulties as a result of the pandemic (O'Connor et al, 2021). Research into previous pandemics suggest that individuals with a history of mental health difficulties are more vulnerable to becoming unwell again, or becoming more unwell, due to heightened stress responses (Esterwood & Saeed, 2020). Young people who have also experienced social disability due to their mental health difficulties, defined as difficulties with social functioning such as interacting with others or engaging in structured activity including work roles (Berry et al, 2022) may also have experienced the pandemic and its restrictions differently. Prior experience of living through significant adversity may also however have developed resilience supporting better coping (Richardson, 2002) which may have helped young people to manage the pandemic in a different way to the general population. Understanding the experience of this population is the focus of the current study.

Aims

The DisCOVery project (Recovery alongside social isolation: Research into the mental health impacts of COVID-19 for young people) aimed to understand the impact and experiences of the COVID-19 pandemic of young people with existing vulnerabilities using quantitative and qualitative methods. Using a section of this data, this project focused on young people with a history of severe mental health problems and social functioning difficulties and explored their experience of the pandemic using semi-structured qualitative interviews.

Research question: What are the experiences of young people with pre-existing mental health difficulties and social disability of the COVID-19 pandemic?

Methodology

This study used semi-structured interviews to gain an in-depth understanding of young people's lived experiences of the COVID-19 pandemic. As part of the wider DisCOVery project, the quantitative data is used to put the sample into context.

Recruitment and Participants

Participants approached to take part in this study had previously participated in the PRODIGY Randomised Controlled Trial between 2012 and 2017 (Berry et al, 2022). PRODIGY recruited young people with severe mental health difficulties and low levels of engagement in structured activity to test Social Recovery Therapy (SRT). Participants were randomly allocated to receive either SRT or Treatment as Usual (TAU). This group was chosen because historically they had both severe mental health difficulties and a lack of structured activity. The focus of the current study was on experiences of the pandemic rather than testing the efficacy of the SRT intervention. However, intervention allocation information is provided in Table 1 for context.

A total of 141 former PRODIGY participants had provided consent to contact with further research opportunities. All were contacted by email and 25 consented to take part in the project. Of these, 19 consented to being interviewed. Of the 19, five did not respond to further contact and one disengaged after agreeing to take part. This resulted in a total of 13 participants. Participants lived in Norfolk or Suffolk, Manchester or Sussex and were all

White British. Demographic information is show below in Table 1. The majority of participants who agreed to take part in this study had not received the SRT intervention during the original PRODIGY trial.

Table 1: Participant Characteristics

DisCOVery ID	Gender	Age	PRODIGY Allocation	Employment status PRE COVID	Living with	GAD7 Score	PHQ9 Score
S02	Female	21	TAU	University Student	Family	Severe	Severe
N07	Female	22	TAU	Currently not working or studying	Family	Severe	Severe
S08	Female	24	TAU	University Student	Friends / Flatmates	Severe	Severe
N02	Female	29	TAU	Unable to work due to disability	Partner / Spouse	Severe	Severe
S07	Male	25	TAU	Currently not working or studying	Family	Severe	Moderate -Severe
N04	Male	22	SRT	Currently not working or studying	Family	Severe	Severe
N06	Male	23	SRT	Unable to work due to disability	Live alone	Moderate	Moderate
N11	Female	27	SRT	Unable to work due to disability	Partner / Spouse	Severe	Severe
N10	Female	26	SRT	Unable to work due to disability	Partner / Spouse	Severe	Severe
S10	Male	30	TAU	Unable to work due to disability	Family	Moderate	Severe
N08	Female	27	TAU	Full time parent	Partner / Spouse	Severe	Severe
N09	Female	27	TAU	In full time work	Friends / Flatmates	Severe	Moderate -Severe
N03	Male	25	SRT	In full time work	Family	Minimal	Mild

Table Key: GAD7=Generalised Anxiety Disorder Assessment (Spitzer, 2006); PHQ9=Patient Health Questionnaire (Measure of Depression) (Kronke et al, 2001); SRT=received Social Recovery Therapy, TAU=treatment as usual, did not receive Social Recovery Therapy

The 13 participants (38.46% male) were aged between 21 and 30. The majority of the sample had ongoing mental health difficulties, scoring in the moderate or above range on both the GAD-7 Generalised Anxiety Disorder Assessment (Measure of Anxiety) (Spitzer, 2006) and the PHQ- 9 (Patient Health Questionnaire (Measure of Depression) (Kronke et al, 2001). Only one participant did not score in the clinical range of either measure. Data from this participant were retained in order to capture the full experience of young people with pre-existing difficulties, as this population will include individuals who are no longer experiencing difficulties.

Procedure

Participants who had consented to be contacted for further research were sent an email or letter informing them of the research aims and instructions to take part. This contained a link or QR code which allowed participants to access the study hosted on Qualtrics. Those who consented were emailed by a researcher to arrange an appointment for the interview and answer any questions. Interviews all took place remotely either by phone (n = 10) or video call (n = 3) in line with COVID restrictions. Interviews lasted approximately one hour. The interviews were semi-structured with an interview guide which was created with service user involvement. Over time, the interviews were adapted to explore participant views and experiences of guidelines changing and views on the vaccine. The interview included questions about how life had changed since the pandemic including employment, relationships, friendships and housing, and how this had impacted the participant's mental health and beliefs about the future. Interviews took place between March and June 2021, during which time there were multiple changes in restrictions. These included allowing outdoor gatherings of six people (29th March 2021), the re-opening of non-essential retail

(12th April, 2021) and indoor entertainment venues (17th May 2021) (UK Government, 2021), and the vaccine was made available to all adults (17th June 2021) (NHS, 2021). Following the interview, participants were sent a £5 voucher to thank them for taking part along with a debrief sheet, including some suggestions of supportive services and resources. The interviews were transcribed by the researchers.

Ethics

The BPS Code of Ethics was followed (Oates et al, 2021). Ethical approval was sought from University of Sussex and Essex Research Ethics Committee (Reference number IRAS 285119).

Analysis

The data were analysed using the Braun and Clarke (2006) method of thematic analysis. This involved identifying codes and developing these into themes to build a coherent narrative representative of all participants. This is aligned with the critical realist perspective (Clarke, Braun and Hayfield, 2015) and supports the critical realism epistemological position of the research.

Reflexivity

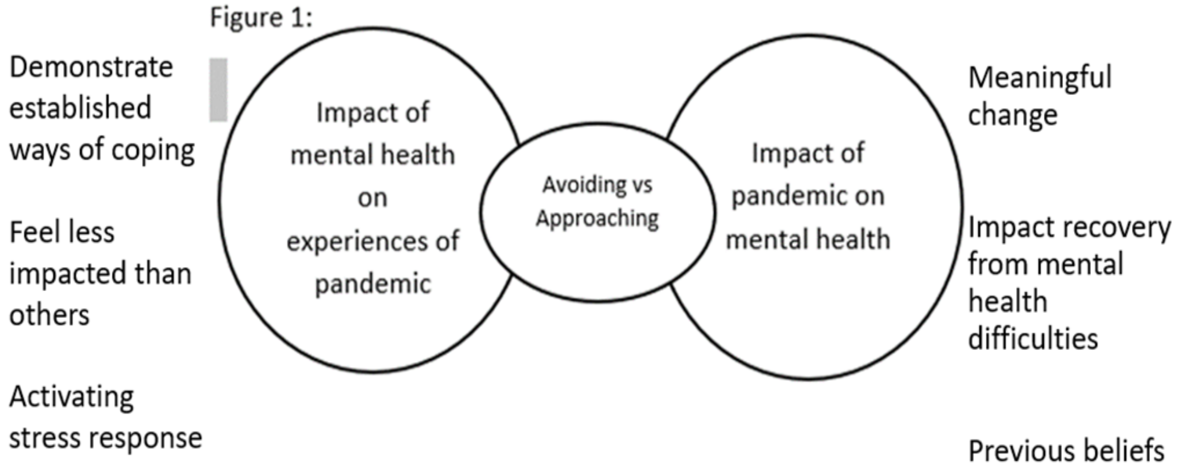
Reflexivity was necessary throughout to consider the researcher position and how this could impact the data interpretations (Green and Thorogood 2018). Supervision, a reflective journal and attendance at a regular qualitative discussion forum supported this.

It was particularly important for the researcher to be mindful about the impact of their own experiences and the impact of COVID-19 as its restrictions have been global. A reflexive journal was kept recording the views of the researcher after interviews and during the analysis. Supervision with the study team further supported reflexivity. This helped to ensure the research is credible and confirmable (Lincoln and Guba, 1985).

Results

Participants' lives and experiences had been impacted by a reciprocal combination of the pandemic and their mental health, resulting in a number of challenges and barriers but also opportunities. From analysing the data, two main themes and six subthemes were identified as shown in Figure 1. In addition, there was a cross-cutting theme of avoiding vs. approaching, referring to the varied ways in which participants responded to challenges and opportunities presented by the pandemic.

Figure 1: Themes and Subthemes



The themes shown in the figure will now be discussed.

Impact of mental health on experiences of the pandemic

This first main theme refers to the way in which participant's experiences and lives pre-pandemic impacted the nature of the challenges they experienced and their responses. There were three subthemes within this theme.

Demonstrate established ways of coping

There were a range of ways in which participants' ability to cope well with the pandemic was influenced by their prior life experiences and experiences of mental health difficulties. Some participants spoke about working and studying, which they continued with despite changes. However, many participants were not in work and described already having an awareness of a need to take control of the way in which they spent their time to protect their mental health. This meant there were some ways in which participants were equipped to cope with the impact of lockdown and self-isolation.

"I'm alone so often, I just make sure I'm doing stuff instead of just sitting around and doing nothing and being miserable." N10

Exercise, housework and spending time in nature were activities the participants described undertaking to fill their time. Ways the participants had learned to respond to difficult thoughts also helped them approach challenging emotions as a result of the pandemic in a different way. One participant described being able to cope better with than they had with difficult experiences previously, using positive self-talk.

"There was a time when I would have been having breakdowns but I think it's a case of telling myself that until something happens it's ok." S10

Participants also described psychological techniques which they had learned in therapy.

"ACT [Acceptance and Commitment Therapy] stuff has been quite useful…noticing thoughts and trying to defuse thoughts instead of going along with everything and start to recognise and catch the spirals as you start thinking about things, especially these triggers" N06

This demonstrates how previous experiences of adversity can support young people to cope with unexpected challenges including the pandemic, and the value of therapeutic support not only in managing current mental health difficulties but also in providing an ability to cope with other adversity that arises in their lives.

Relationships were also an important part of coping. Many participants remained close to their families, some continuing to live at home. Though some of the participants reported not having close friendships, for those who did friendships had been experienced as having been supportive through previous periods of difficult mental health as well as COVID-19.

“We spend a lot of time together anyway, like we have for the last 10 years...My little group they really kept me going…if I hadn't been with my three closest friends, I would have felt it a lot more.” S08.

Participants generally reported positive relationships which were not significantly adversely affected during the pandemic with at least one other person, including partners, families and/or friends. These appeared to be strong relationships where they felt comfortable and safe to seek support in times of difficulty, having done this during periods of poor mental health.

This theme demonstrates ways in which participant’s previous experiences supported them in coping with the challenges of COVID19.

Feel less impacted than others

Participants recognised that the world had changed significantly. However, there are ways in which some participants felt less impacted by the pandemic. Most participants described having few friends, and feeling more connected to their families or partners they lived with, relationships which were less impacted by social distancing guidelines. Before the pandemic, having few friendships and activities outside the house felt more uncommon and one participant described a comfort in knowing that other’s lives were now more similar to her own:

"That sense that lots of other people are in the same situation. At least you're not alone being stuck at home. Before I was seeing everyone else moving on with their lives, stuck in my room, just merely existing. Taking each day at a time. Struggling to shower each day, not going outside much. Lots of other people not being outside much, stuck at home – at least there's a sense that you're not quite such an odd one out." N02

This suggests that for some, the pandemic may have allowed individuals to feel more connected to society as other's lives had become more similar to theirs, and because their lives had already been significantly impacted by their mental health difficulties, less had changed so the impact of the pandemic itself was reduced. However this also reinforced how difficult change felt:

"I just worry that I'll just still be the same and just not be able to move on and be at home still…just wasting more of life…Especially if you've already been doing it for a long time. Sort of as you get older, losing hair…thinking you've passed your time. So seeing it's March again, anniversary of the pandemic, and how much do you have to show for it. And the worry is that nothing much will change or I won't make the progress I want to make" N06

Because things had been difficult for such a long time, it is difficult for participants to believe that things could be different, and there is comfort for them in others becoming similar, rather than believing they their lives could improve.

This theme demonstrates that participant's lives have in many cases changed less because of the pandemic because their lives were already significantly impacted by their mental health. This may provide some comfort but may also reinforce feeling hopeless that change is not possible.

Activating stress response

As well as providing tools to cope, there were also ways in which participants previous experiences of mental health difficulties intensified the challenges of the pandemic. Participants described how the pandemic directly increased anxiety including health anxiety and panic:

“When people panic, that makes me panic. And obviously the whole world is panicking” N07

As well as this, the pandemic also increased symptoms of depression, including feeling low, hopeless or lacking in motivation:

“Lockdown has made me a lot more lazy than I ever thought possible. I have very, very little motivation and I very rarely want to do anything” N04

The pandemic represents a time of significant stress and as well as coping skills participants have established, they also have established responses to stress which have been activated. Some participants returned to coping strategies they had experienced previously such as withdrawal or overeating:

“I have gained a lot of weight in this time… I have a very long history of an eating disorder and so…I used food to cope with it…It was quite naive of me at the beginning to think that this whole pandemic wouldn't affect my relationship with food” S08

This demonstrates that even where participant’s lives have been less affected by changes, mental health difficulties have intensified distress which has been difficult to cope with.

Impact of pandemic on mental health

This second main theme refers to the ways that participant’s experiences of COVID-19 and the restrictions and changes then affected their mental health.

Meaningful changes

For some participants, the pandemic had facilitated making positive changes, leading to improvements in their mental health. This had happened for a range of reasons including the increased availability of online opportunities which are often easier to access, friendliness of neighbours or communities, a realisation that isolation was not desirable and an unexpected ability to adapt to restrictions:

“At the beginning of the pandemic there was troubles with food stock…Because of autism I would only eat certain things, I couldn't get them so I had to obviously eat other stuff. So in a way, the pandemic’s actually helped me overcome sensory issues in terms of food, so I'm actually eating a lot more varied food now.” S07

This demonstrates some ways in which the pandemic has resulted in positive life shifts which may not have happened in another way. Capacity to build on these changes can lead to further improvements in their mental health:

“Starting with this course and then every week and every day, I look for jobs. I feel a bit more, I can’t really think of the words? I feel a bit more OK” N11

This demonstrates both that meaningful change is possible due to opportunities provided by the pandemic and that small actions can lead to significant improvements.

Impact recovery from mental health difficulties

Conversely, some participants spoke about the ways the pandemic had impacted the progress they were making to improve their lives. Though some participants were able to adapt to the changes and restrictions, for most this made life more complicated:

“It’s taken such a long time to get the confidence where I am now and to be able to even get on the bus, it’s something I was never able to do and I can do now…I want to go out there and almost prove to myself that I can do these things and the fact that I can't and I don't know whether it's because I can't or whether it's because I'm not allowed" S02

Participants now need to consider whether if it safe to challenge their anxiety by understanding whether this is attributed to the real threat of the pandemic or their previous mental health difficulties which they had been working to challenge. This extra mental process compounds the difficulty in deciding how safe it is to move forwards.

Participants described extensive experience of different mental health services over many years as difficult to access and unhelpful. Participants believed that services were unwilling or unable to support them, and so struggled to articulate what support they needed which services could provide. Anxieties about accessing support had increased as a result of the pandemic. Participants described being anxious about service pressures and long waiting lists and found that accessing support had become more difficult:

"I had to go to A&E and be like I'm actually really not OK and then they chased up the eating disorder clinic because they weren't replying to me." N08

Participants with already negative impressions of mental health support, as well as anxieties about availability of support, may deteriorate quite significantly before they ask for help. This, as well as the disruption caused by impact of the pandemic, may further negatively impact their progress.

Previous beliefs

For many participants, the pandemic reinforced existing beliefs that the world, or other people, were unsafe. Participants described fears of the virus, or other global disasters which they believed would impact their ability to live the life they wanted, and felt the virus demonstrated a reality which they were ready for:

“I was quite well prepared for the lockdowns because I’ve barely been out myself...I didn’t leave the house at all... I’ve been preparing for this for years really” N06.

Many of the participants described negative beliefs about others, and behaviours such as aggressiveness in shops, refusal to wear masks or stockpiling supplies when these were running low, increased beliefs that others were selfish, unkind or hostile.

“I've always had a problem with the British public…there's such a clear like, got mine attitude…it's prevalent in the UK and I hate it.” N10

A small number of participants described they had witnessed kindness which they had not expected, which may lead them to re-evaluate their expectations of others; though this was a minority, it does demonstrate that changes in beliefs were possible for some of this group. Generally however, the pandemic provided many opportunities for beliefs developed through prior negative experiences to be reinforced.

Avoiding vs approaching

Avoiding vs approaching was a cross-cutting theme across both the impact of the pandemic and the impact of mental health for most participants. The way in which participants viewed their future demonstrated these opposing views:

“I always have found it difficult to pinpoint and to think about future, but I think COVID has made that even worse.” N04

Participant’s difficult experiences led to increased avoidance, which was reinforced both by the stressful experiences caused by the pandemic and the message that remaining safe meant staying at home:

“For someone who was just about to really come out of their shell and look at the world in a brighter place and try and get myself out there only for all this to then happen like a big kick in the teeth, you’re like “oh, how dare I try and do something with my life”” S02.

This demonstrates the multiple ways in which the pandemic reinforced avoidance. Approaching refers to approaching difficulties and opportunities, which both a history of mental health difficulties and the pandemic have presented. Some participants had developed new goals following making life changes during the pandemic:

“In a year’s time…hopefully I'll be in the second year of my course. I hope to be doing more research, getting more experience in healthcare, trying to have a…well rounded, wholesome, holistic life.” N09.

For another participant, their goals remained the same, even though they were not possible to reach currently:

“the goals I had…just postponed 18 months or so” N03

Participants with pre-existing goals and hopes for the future had created these despite difficult experiences of managing their mental health and in doing so, had demonstrated to themselves the importance and possibility of important goals and approaching their future despite adversity. Others had been able to adapt to changing circumstances to create a different vision of the future. This shows the extent to which participants avoidance or approach attitudes impacts their outlook and plans, views and expectations for their future.

Discussion

This research explored how a group of young adults with a history of mental health difficulties and social disability were impacted by the COVID-19 pandemic and identified two main themes; the impact of mental health of the pandemic, and the impact of the pandemic on mental health. Avoiding and approaching perspectives were present in both themes and demonstrate some of the differences in attitudes across the sample. Although the pandemic was in many ways more challenging for participants with pre-existing difficulties, their previous experience of managing adversity did provide skills and knowledge which supported the participants.

There were many aspects of the pandemic which made participant's lives more challenging. Participants had a range of pre-existing mental health conditions and the majority were still experiencing significant mental health challenges, as demonstrated by the PHQ-9 and GAD-7 data. Data from qualitative interviews provided insight into how such difficulties may influence responses to the pandemic, for example by reinforcing patterns of avoidance and their core beliefs about the world being unsafe. The pandemic has also increased exposure to risk and distressing experiences, increasing anxiety and activating established stress responses. Research into previous pandemics described how individuals with a history of mental health difficulty are at increased risk of distress due to heightened stress responses, which will understandably reinforce the drive to avoid (Esterwood & Saeed, 2020). Established avoidance may explain why some participants felt less alone when guidance was to stay at home and have less contact with others, as this became acceptable. This does not mean that lack of friendship was less distressing for these participants but that this distress was not caused or worsened by COVID-19.

Many participants described that the pandemic had impacted their confidence and capacity to make progress in improving their mental health. Participants demonstrated an understanding of the need to challenge their beliefs and reflected on the uncertainty of how safe and appropriate this was now to do. Cognitive Behavioural Therapy (CBT) is the most commonly used therapy in the NHS (Moller et al, 2019) and aims to help people learn their fears are 'irrational' by exposure to them (Beck, 2011). The pandemic is not an irrational fear and participants described feeling frustrated that the way they had previously learned to address their mental health was less helpful. Participants also described anxieties about seeking support and a belief that lack of support would further negatively impact their ability to make changes. The sample consistently described a longstanding lack of faith in services and their ability to cope now with an influx of individuals requiring treatment. It is recognised that mental health services have been struggling to meet individual's needs for some time (Iacobucci, 2019) and services are now under even higher levels of pressure (Abbas et al, 2021) and the participants appeared very aware of this.

However, there were a number of ways in which the participants had developed strengths due to their experiences of adversity pre-pandemic. Participants demonstrated an awareness of the way they manage their mental health, which individuals who had not experienced adversity previously may not have. This was evident in three ways.

First, participants described an understanding of the importance of routine, and those without employment or study were able to apply their experience of managing their time in the absence of this being imposed on them. A part of this also included undertaking specific activities to deliberately benefit their mental health, such as exercise and spending time outdoors. The pandemic has caused significant disruption to routines for many young people due to the closure of schools, universities and workplaces (Young Minds, 2021). Routine and structured activity is understood to be important for positive mental health (Goodman et al, 2017), and participants experienced in managing routine without external structure showed a good awareness of this.

Second, participants described how they used psychological techniques which they had either identified themselves or learned in therapy. One example of this was acceptance. Acceptance and Commitment Therapy (ACT) aims to support individuals to embrace and accept difficult emotions, rather than fighting them (Hayes et al, 2011). The therapy has been used in the general population, and has found good results, suggesting that acceptance can help individuals to cope with the emotional impact of the pandemic (Shepherd et al, 2021). A further psychological technique which participants employed was compassionate self-relating. Compassionate approaches such as Compassion Focused Therapy (CFT) describes this as a way of an individual soothing themselves by providing calm and gentle reassurance which helps soothe the nervous system (Gilbert, 2009). These are techniques participants learned either through therapy or independently to help them manage their mental health without exposure to feared stimuli which may pose a genuine threat and were able to apply these to managing stress from the pandemic.

The final way of coping participants utilised was seeking support from others. Many of the participants did not have wide social circles and for these participants, family or partner relationships were particularly important. Participants described understanding the importance of others in helping them cope with difficult situations. Being part of a social or family group is an evolutionary need to keep us safe from external threats (Schaller et al, 2013), and meaningful relationships support good overall health (Umberson & Karas Montez, 2010). Within the general population and specifically young people, there is an increased risk of developing loneliness due to COVID (Loades et al, 2020). Existing friendships and family networks appeared the most helpful in this sample, with even participants with small networks finding this support from people who were important to them.

There were also ways in which participants achieved meaningful change due to the pandemic. Living through changes brought about by COVID-19 has represented an opportunity for individuals to reflect on their lives (Hennekam et al, 2021). Changes can be small initially and an ability to build on small changes is a positive predictor of recovery in mental health (Shepherd et al, 2010). Participants who managed to make changes could clearly cite where their motivation came from. Often participants were surprised by changes or their results, suggesting change is possible even when it does not appear that way. Approaching difficulties as challenges, sometimes working harder to do this in a time of adversity leads to resilient reintegration (Richardson et al, 1990). Resilience is well known to support individuals to thrive in times of stress and so participants who were able to make positive changes will be better equipped to handle future adversity.

Some participants had pre-existing goals or goals developed during the pandemic. Goals and motivation are strongly linked to recovery and clearer goals are more likely to be achieved (Goales et al, 2005). Holding onto aims and plans despite adversity is another example of approaching, rather than avoiding challenges, and further supporting building resilient reintegration (Richardson et al, 1990). Participants who see adversity as an opportunity for growth are more likely to develop this resilience (Mosanya, 2021).

Clinical implications

First it is important to recognise that the participants in this study felt disappointed with services and had experiences of support being unavailable, unhelpful, or of not meeting their needs, which may lead them to be reluctant to seek help again (Dawson, 2021). Of the sample, 12 of the 13 young people were still managing high levels of depression and anxiety symptoms. If young people do not receive the support they need, they may face long term impacts which may impact their mental health throughout the lives (McGorry & Mei, 2018.) This shows the importance of services working to re-engage individuals like those in this group, The Young Minds Report (2021) states that consistent community mental health support is essential to prevent widespread long-term impact. It may be beneficial to take a strengths-based approach, based upon individual's skills and strengths as opposed to deficits (Roberts & Boardman, 2013). This research suggests several ways in which practitioners could support young people with pre-existing difficulties through and after COVID-19. This may involve different psychological therapies, specifically those which support coping with difficult emotions including ACT or CFT rather than promote exposure or challenge core beliefs like CBT. Psychoeducation on approaching adversity as challenge and how this promotes resilience, may also be of benefit. More practically, supporting individuals to adapt a routine and filling their time with a range of activities which may boost their mental health and support recovery. There may also be a role for services to support individuals to build links with others through community activities and befriending, allowing individuals to develop meaningful connections and providing an additional source of support. Finally using motivational interviewing to understand how change could benefit them (Rollnick & Miller, 1995) and to support young people to develop and keep hold of goals, promoting and building on small positive changes may support wider recovery.

Research implications

The nature of the pandemic has changed significantly over the time this research paper was written and COVID-19 continues to impact lives across the world. Longer term research is required to understand the impact on the mental health of this population over time, and identify both challenges and opportunities, allowing results to influence and develop services. This study shows the benefit of maintaining connections with former participants of studies, particularly with groups which are harder to engage as a way of involving their perspective in research.

Limitations and strengths of study

There are some limitations of this study. COVID and the restrictions have fluctuated significantly in the UK since March 2020 and these interviews took place at one time point, participant's lives and feelings may have changed significantly since then. COVID-19 has had a range of impacts on young people. A sample of 13 cannot include people who have been affected in all the ways. None of the sample had suffered a bereavement, none had experienced economic consequences and only one had had COVID-19. A group which had been impacted in different ways may have had very different experiences of coping.

All interviews took place remotely, due to COVID-19 guidelines. This may have impacted the researcher's ability to build rapport, and as such the participant's ability to share honestly. As well as this, all participants were White-British and were a small proportion of the original PRODIGY participants, so the sample was not representative of this group or of other ethnicities. In addition, whilst it is important to acknowledge the strengths that some of the participants were able to apply to support coping or continuing to move forward, it is also important to highlight that other young people, including those from different clinical populations, those who have not found ways of coping with their mental health, or those for whom the pandemic has significantly impacted their coping strategies, may not have been able to do this in the same way.

However, there are a number of strengths of this research. The participants made up a particularly unique group. The PRODIGY sample was made up of young people with both a history of severe and enduring mental health difficulties and a social disability, and as such are individuals with more complex needs. In addition, the participants' difficulties started several years ago, and so all participants had years of experiences of living with, and managing, their mental health difficulties. This was a group who were largely not in contact with services and as such are not usually possible to reach in mental health research. By understanding their perspective, this research adds to the literature about how to best support individuals with long term and chronic mental health difficulties during this pandemic and other times of significant stress. Completing qualitative research allowed for a more in-depth understanding of their experiences.

Conclusion

COVID-19 has impacted the lives of young adults significantly, and this sample have also been impacted by their long-standing mental health difficulties. COVID appears to have reactivated stress responses for participants increasing their distress, made making progress with improving their mental health difficult and reinforced negative beliefs about others, themselves and the future, as well as patterns of avoidance. However there are some ways in which their experiences of coping with adversity supported them to manage the pandemic and their mental health. This included utilising helpful coping strategies, finding support in relationships, making meaningful changes and building towards a more hopeful future. Professionals and services can support young people through and beyond COVID-19 by helping them to implement some of these ways of coping and building on small changes.

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Chapter Five: Additional Methodology

The aim of this chapter is to provide additional context around the empirical paper by providing supporting information. This will consist of providing background information of the study, including the epistemological position, expanding the methodology by providing more detail on the ethics, and concluding with the analysis, considering the impact of reflexivity and describing how the final themes were reached.

Background: Epistemological Position

The ontological position of the researcher is important because it makes an assumption about whether the reality is objective, or always influenced by individual perspective (Braun & Clarke, 2013). These opposing positions are referred to as realism and relativism (Braun & Clarke, 2013). The position taken in this research was the critical realist perspective. This position suggests that our experiences and perspectives are constructed by our past experiences and influenced by culture (Bhaskar et al, 1998). To best understand an individual or group perspective, we therefore most first understand that the way in which they experience a phenomenon is dependent on their prior experiences or beliefs. This felt important because COVID-19 has had a global impact, and there is a common narrative that we have all been equally affected, referred to in one study as “the lie of solidarity” (Nolan, 2020). In using this approach, the researcher made a deliberate decision to centre participant’s experiences , rather than global experiences of COVID-19. The global experience of COVID-19 is important but is already being captured with over 200 studies investigating different impacts of COVID-19 in the general population (World in Data 2022). Therefore, a qualitative approach investigating the experiences of young people with pre-existing mental health difficulties using a critical realism approach was chosen.

Methodology

Ethics

The British Psychological Society's Code of Research Ethics (Oates et al, 2021) was followed, and UEA and NHS procedures were adhered to, as detailed below.

Only participants from PRODIGY who consented to be involved in further research were contacted. A Participant Information Sheet was provided for all participants who were interested in taking part in the research. All participants were asked to provide written informed consent. This was completed virtually, with participants required to confirm agreement to statements before they were able to progress further and complete the quantitative survey. One statement was regarding contact for interview. Participants were then contacted by email and offered the opportunity to answer any questions and an interview time. In this email, participants were also asked to provide contact details of their GP and informed that if they suggested that they or someone else was at risk, the researchers may need to contact their GP to ensure safety.

Before the interview took place, the participants were told that they were able to end the interview at any time or decline answering any questions they did not wish too. They were also reminded that deciding not to take part would not impact their usual care.

There was no deception at any time.

At the end of the interview, participants were thanked for taking part and sent a debrief sheet with contact details of further support.

With regards to data security and confidentiality, no names were used in the transcripts and all participants were allocated numbers. The transcripts and recordings were stored on

University and NHS servers and was only accessible to researchers within the DisCovery team.

Reflexivity

Reflexivity is the process by which the researcher understands and acknowledges the role that they have in the research (Reinhart & Reuland, 1993). This was particularly important for this research as COVID-19 has had significant global impacts and affected the researcher's own life. In addition to this, the researcher had met some of the participants as part of PRODIGY where she was an assessor on the trial, so it was important to be open about this experience and the way that it may impact the research. More widely, reflexivity supports credibility, one of Lincoln & Guba's four criteria of qualitive research (1985) as it was a way to limit researcher bias.

Keeping a reflective journal and supervision are both ways to support reflexivity (Watt, 2007) and both were undertaken to support the research. Reflective journal extract:

"Reading the transcripts, I am struck by the contrasts that exist within the sample. I know that all the participants have experienced severe difficulties in the past, and some have managed to move through these whilst others feel stuck. What is the difference between these two responses and how can I make sure both perspectives are evident in the analysis?" June 2021.

Keeping a journal was particularly helpful to return to as ideas changed, ensuring that codes and initial impressions were retained.

Analysis

Thematic analysis is a six-step inductive process whereby the themes are identified within the data, rather than applying specific ideas and searching for supportive evidence (Braun and Clarke, 2006). This type of analysis was chosen because this type of analysis is aligned with the critical realist perspective (Clarke, Braun and Hayfield, 2015), so supported the epistemological position of the research.

The way that these stages were applied will now be described.

1. Becoming familiar with the data.

   Transcribing the data was a helpful way for me to become familiar with the data and begin to think about initial themes. I undertook and transcribed nine of the interviews, with four being undertaken and transcribed by a DisCOVery interviewer. Transcription is identified as a helpful step in this early stage (Kisely & Kendall, 2011). I made sure that I spent more time reading the other interviews, including reading them aloud, to limit the impact of not having completed the interview or transcription.

2. Generating initial codes

   After becoming more familiar with the data, I spent some time with printed copies of the transcripts noticing repeating ideas and adding annotations. It was here were I started to notice the contrasts within the data and this became a big part of my analysis.

3. Searching for themes

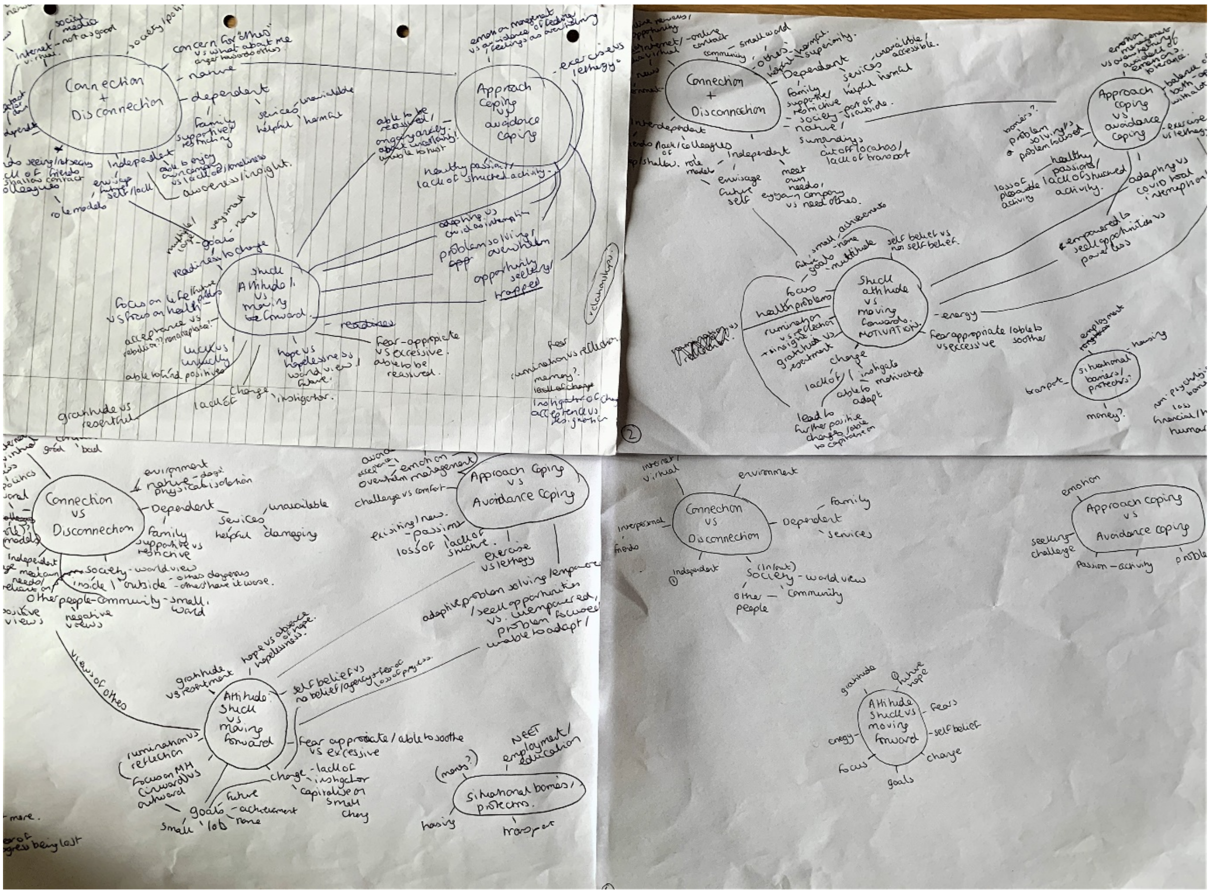
   I began building up the annotations and considering wider themes. My reflective diary was particularly helpful here as I needed some space to think about the ideas that were forming. I began to think about connection and disconnection, approach and avoidance coping and stuck and moving forward as being main themes, and how these could be used to tell the complete story of the data, rather than privileging one perspective over another.

4. Reviewing themes

Supervision was helpful to think about reviewing themes. One discussion involved thinking about removing one participant as his presentation was quite different from some of the other participants due to working full time and not reporting current mental health difficulties. We spoke about how his voice was an important part of the story and could be included by using the contrasting themes. This also involved starting to build a database with quotes.

5. Defining and naming themes:

The themes changed names slightly during this part of the process. The pictures below show how the themes changed over time, and how the codes supporting them became reduced as I began to feel more confident in using the essence of the themes to tell the story of the data.



Following discussion in supervision, I changed the focus of the analysis in significant ways. Firstly, I edited the main themes to coping connection and future hope, using barriers and facilitators became sub-themes. However this still did not create a cohesive narrative, and it was necessary to reconsider how themes could be used to do this succinctly and clearly. It started to feel that there were two impacts on participants responses evident in the data – their mental health, and the pandemic. Avoidance was a subtheme that appeared to relate to both.

I started to separate my themes into the impact of mental health on responses to the pandemic and the impact of the pandemic on participant's mental health. I was able to re-position the ideas into these two categories using subthemes. This allowed me to tell the story by summarising the participant's experiences, describing the contradictions in a more coherent way. The presence of avoidance was clear across both themes but it was clear this was a factor for some participants more than others, and "approaching" was used to conceptualise the experiences of participants who approached challenges and opportunities, rather than avoiding them. Views of the future were used to demonstrate this, taken from the "moving forwards attitude" theme.

The table below shows where the old themes fitted in:

Table 1: New and Old Themes

Impact of mental health on experiences of the pandemic	Impact of pandemic on mental health
Demonstrate established ways of coping: Existing connections / relationships; use of activity; acceptance / management of emotion; use of learned therapeutic techniques	Meaningful change Able to make positive adaptations; able to access new opportunities; able to capitalise on positive changes
Feel less impacted than others Connected / disconnected from society; lack of change	Impact progress on mental health Unsure whether safe to challenge fears; lack of support from services

Activating stress response Unhelpful coping strategies; triggers overwhelming emotion	Previous beliefs Reinforcing beliefs about others
Avoiding vs approaching Views of the future and the extent to which participants were able to approach the future hopefully or whether they avoided this as it was too overwhelming	

6. Writing the report:

Writing the report was an important part of the analysis and it was only during supervision after completing the first draft that I was able to see my themes did not fit together well. This allowed me to rework the themes to be organised under impact of the pandemic of mental health and impact of mental health on response to the pandemic. Following feedback on the first draft, I re-wrote the report with far fewer quotes and needed to make difficult decisions about which quotes to keep and which to leave out. This was challenging as I wanted to make sure all my participant’s voces and experiences were heard, but I found actually having less, but more representative themes made this easier. Both themes included beneficial responses and responses which made coping more difficult, and I was able to describe this contradiction in the discussion section.

Chapter Six: Discussion and critical evaluation

This thesis aimed to explore the benefits of integrated mental health and social care for a youth population, as well as explore ways in which young people with pre-existing mental health difficulties had experienced the COVID-19 pandemic. Youth is a critical developmental period (McGorry & Mei, 2018) and so identifying ways to support young people with challenging life circumstances is crucial.

This chapter will present the findings of the systematic review and then the empirical paper. It will then provide a critical evaluation, considering the strengths and limitations of both papers, before providing clinical and research implications of the complete thesis. The chapter concludes with general reflections, an outline of the dissemination plan and overall conclusions.

Summary of Findings

Results from both studies inform approaches to youth mental health. The systematic review synthesized the results from 12 papers. Nine of these evaluated different integrated interventions, with qualitative papers and a discreet choice experiment providing data regarding service user experience. The study found evidence to support integrated social care and mental health services in improving the service user experience for young people, limited evidence in in improving clinical effectiveness and no evidence regarding cost efficiency.

The empirical project explored the experiences of the COVID-19 pandemic for 13 young people with previous experiences of mental health difficulties. The results found that young people's mental health impacted the way they responded to the pandemic, and the pandemic also impacted their mental health. This meant that the young people were managing multiple stresses which made their lives difficult. However, the participants had also developed ways of managing stresses which were helping to support them in coping with the pandemic, suggesting that existing strengths and experiences of managing prior adversity could be utilised to managing the impact of COVID-19. A tendency to approach or avoid challenges was also seen within the sample and influenced participant's responses and views of the future.

Taken together, the papers indicate the importance of the right method of intervention and the value of holistic support, and of services being available to young people with mental health difficulties. They also demonstrate the cost of not intervening, in that young people's difficulties persist and get worse, when navigating future challenges.

Critical Evaluation: Strengths and Limitations

This thesis portfolio has some limitations. One limitation is that both projects capture research from specific times. The systematic review only included studies which took place before COVID-19. The needs of young people and the resources available are likely to have changed and possibly increased, since the studies took place. Integrated services, like other NHS services, likely had to adapt and many may keep some of these changes longer term, such as some online service delivery (Power et al, 2020), which this review does not capture. With regards to the empirical project, the interviews took place at only one time point for each participant. During the time of the interviews (March – June 2021), there were a number of changes with regards to restrictions and the impact of vaccinations. Because of this, participants' experiences and emotions may have been very different from each other, as research indicates that young people's emotions and mental health have fluctuated over time and been influenced by changes in the pandemic (Green et al, 2021). Part of the interview involved asking how the way that participants have felt over the course of the pandemic has changed. This involved the participants thinking back for a year or more. Fuzzy trace theory (Reyna & Brainerd, 1995) states that memory is unreliable, and retrieval is influenced by current circumstances and emotions. This means that it would have been difficult for participants to provide fully accurate information about their past experiences. Interviews earlier and later in the pandemic would have given a broader picture and increased the dependability and credibility, suggesting greater consistency and confidence that the results are "true" (Lincoln & Guba, 1985) and the wider research team planned to complete follow-up interviews to account for this. As the impact of the pandemic continues, participants' perspectives and experiences may also have changed since the interviews.

Another issue of both papers is generalisability. With regards to the systematic review, 11 of the 12 studies identified were not from the UK and so the results are less relevant to the health systems and challenges that exist within the NHS. There were no randomised control trials in the studies which is common in this type of research (Grossman & Mackenzie, 2005); however the appraisal tool (Effective Public Healthcare Panacea Project, EPHPP) rated all studies as of weak-moderate quality and could not take account of the complexity of assessing this type of evidence. Considering the empirical paper, COVID-19 has had a range of impacts on young people. A sample of 13 cannot include people who have been affected in all the ways. None of the sample had suffered a bereavement, none had experienced economic consequences and only one had had COVID-19. All participants were White-British and were a small sample of the original PRODIGY participants. The data in this project are only able to share the experiences of its participants and is not generalisable more widely. A further limitation of the empirical paper was that only the experiences that participants felt comfortable and able to share were included. Most interviews took place on the phone and a small number on Zoom or Attend Anywhere. This was in common with most local NHS mental health services due to social distancing restrictions (Power et al, 2020). It is more difficult to build a rapport in a short space of time without being in person (Carter et al, 2021), and this may have impacted what the participants were willing to share.

A further challenge of the review was its use of social care. Social care itself is known to be a complex topic for a systematic review, largely because it covers a vast topic area which is difficult to define (Long et al, 2002). Having a team complete the searches and sorting articles into categories may have meant that some studies were rejected or included based on individual's criteria rather than a pre-set definition. Similarly in the empirical project, the interviews were not all carried out by the same researcher, and this may have resulted in some slight differences in interview experiences for participants, and the data obtained.

However, there are a number of strengths to this thesis portfolio, some of which mitigate the impact of the limitations. Joining wider teams allows the researcher to make a larger contribution to the literature, and the individual papers benefitted from the support and expertise of a wider team network. For the systematic review, having a wider team allowed independent checking and concordance with all aspects of screening, extraction and critical appraisal. For the empirical paper, the team supported reflexivity. Discussions were particularly helpful in adapting the interviews following changing restrictions and in early parts of the analysis, allowing for better credibility of the research (Lincoln & Guba, 1985). Both projects were also developed using patient and public involvement, ensuring that the questions of most importance to service users were considered. As part of wider projects looking to understand the impact of COVID-19 on the needs of young people with longstanding difficulties and the services supporting them, the results are able to obtain a deeper understanding of young people's experiences of the pandemic, and will also be able to make a stronger argument about the types of support which may be helpful.

There were also strengths of the research methods. In the systematic review, the searches were thorough, using multiple search strands. A strength of the empirical paper was the analysis method. Thematic analysis is recommended by Braun and Clarke (2006) for novice researchers. Using this approach facilitated the identification of codes which allowed the full scope of the data to be presented. In addition to this, individual and team supervision as well as a reflective journal supported the researcher to feel more confident in refining the themes. The participants had not experienced some of the impacts of COVID-19. However, as the interviews continued, it became clear that the same themes were present and no new themes were emerging, known as data saturation (Braun and Clarke, 2021), so it is unlikely that further interviews with this population would have facilitated further insight.

A further strength of the thesis is the way it develops the literature. Because social care systematic reviews are complicated to complete, not many exist (Long et al, 2002). With regards to the qualitative project, this research specifically identified and targeted a group that often do not have the opportunity to have their voices heard. This makes the research valuable as makes a unique contribution and also demonstrates a strength of the PRODIGY project having a pool of engaged research participants who would otherwise be difficult to reach. A qualitative methodology adds a more in-depth understanding of individual experiences and compliments the significant body of quantitative research which is currently taking place. In this way, the two papers in this thesis offer a new contribution to the evidence base.

A strength of the thesis is its clinical and research implications, which will be discussed below.

Clinical Implications

The results of the papers have implications for clinical services. The participants in the qualitative study described a lack of faith in receiving the support they needed from mental health teams. Young Minds (2021) recognises the need for services to offer support to young people to reduce the impact of the pandemic on their mental health. In the UK mental health services are struggling to meet demand. This was true before the pandemic, with only 25% of young people with a mental health need accessing services in 2015 (NHS, 2015). COVID-19 is likely to have increased the need due to multiple increased stresses for young people and services needing to respond to high demand (Power et al, 2020).

Engagement is an essential first step in accessing services (Burns et al, 2013) and is linked to successful treatment outcomes for young people (Ryan et al, 2021) and a strong, non-judgemental relationship with a congruent therapist are considered essential and also sufficient to achieve change in person centred approaches (Rogers, 1951). Engagement was also an aim of recruiting for the PRODIGY project and individuals who did not receive the treatment as part of the trial, or who were ineligible, were signposted to mental health services (Berry et al, 2022).

Participants in the qualitative study were largely not engaged with services at the time of the interview. This was partly because they had anxieties or experience of support not being available but also because they had not found services helpful, or did not receive the support they felt they needed. Other qualitative research supports this finding and suggested that being let down by services makes young people reluctant to seek help again (Dawson, 2021). Many reported continuing to struggle with their mental health and the pandemic was an additional stress to manage. Without receiving support, mental health difficulties can persist and get worse (McGorry & Mei, 2018.) This is because change can become more difficult later in life as unhelpful thought patterns become more ingrained (Beck, 2010) and opportunities are reduced (McGorry & Mei, 2018). There are high economic and societal costs associated with chronic mental illness including that parental mental health can influence the developing mental health of their children (Knapp & Wong, 2020), so leaving mental health problems unaddressed can leave a legacy for future generations. A further argument for early intervention is that it is more cost effective overall (Vyas et al, 2015). Participants in the qualitative study are at risk of longer-term impacts.

There is therefore a need to identify and create services which can sustainably support young people with their mental health. Although the review found limited evidence to support clinical effectiveness, it did suggest that integrated mental health and social care improved young people's experiences of services, which may help young people like those in the qualitative study with disappointing prior experiences. Following COVID-19, services will need to re-evaluate priorities with many services continuing to offer more online services (Johns et al, 2021), there may be less space for the "one stop shop" approach that many of the integrated care intervention studies utilised. However, this may bring opportunities for new types of services to better manage the need. Participants in the qualitative study would not have fitted into any specific hard to reach group but may have benefited from interventions that were easier to access and offered support more widely than just mental health. This suggests that though social care issues can impact mental health, and integrated care may support those young people experiencing both social care and mental health issues, this may not be necessary for all young people in accessing support for their mental health and so provision should be universal and not solely targeted at hard-to-reach groups. Integrated mental health and social care may help in other ways, for example with accessing employment or education, which some of the qualitative participants did not feel would be possible without support. The results of this review suggest that integrated care can improve service user experience. There may be other ways in which integrated care could support this through the new Integrated Care Systems (ICS) which are currently being implemented (NHS, 2020) which may become clearer over time.

COVID19 has understandably increased pressure and distress for young people with pre-existing mental health difficulties and some of this population may benefit from additional support. However, there were many ways in which participants were able to use coping strategies they had developed to manage the impact of the pandemic, or ways in which the pandemic had led to improvements or positive adaptations in their lives. These are examples of resilience integration, whereby individuals experience growth or develop insight due to life stresses or disruptions (Richardson, 2002). Young people could be well supported using a strengths-based model which builds on their existing strengths (Roberts & Boardman, 2013) and psychoeducation about the role of resilience may provide a starting point. Integrated care could make use of this, supporting young people to understand their experiences of managing adversity and the skills they have learned through this could support them in facing social care challenges. Practitioners could also use therapies which develop skills to accept difficult emotions. Acceptance and Commitment Therapy (ACT) aims to facilitate living a meaningful life in line with values, despite difficult circumstances (Hayes et al, 2002) which fits well with coping with the pandemic. Facilitating connection for individuals as part of treatment, including befriending or community services, could also form part of a treatment plan to support participants to develop their social networks, which is another area integrated care could support. Thinking about or avoiding the future was a further theme in the sample and clinicians holding hope, and gently encouraging planning for a better future can form an important part of therapy (Flaskas, 2007). For participants who find this difficult, motivational interviewing may support them in understanding how change could benefit their lives (Rollnick & Miller, 1995), and integrated social care practitioners could also use these techniques to support participants to make practical changes to improve their lives.

Research Implications

There were several research implications from the studies.

The systematic review identified that there is limited evidence, particularly UK and NHS evidence, with regards to integrated mental health and social care services. Some of the questions the review aimed to address for example regarding integrated care reducing waiting lists and improving access to treatments and services are of concern to young people in the UK (Powell & Townsend, 2021) including the qualitative participants in the empirical paper. However, there were no data to evaluate the impact of integrated care on these areas. This may be because 11 of the 12 studies took place outside of the UK, and the issues and pressures which are pertinent to service users and services here in the NHS are different. NHS Trusts generally complete service evaluations within specific settings but these are often not published (Chen & Fawcett, 2019). It is possible that this research is already taking place and publishing findings would allow conclusions to be applied more widely. To consider the wider impact and benefit of integrated care, research which is able to measure costs is needed. This should include comparisons of both short term and longer-term cost and saving and would help commissioners understand the value and efficiency of integrated services.

All of the studies in the review took place before the impact of the COVID-19 pandemic. Like other services, integrated care has likely had to adapt, with many services moving online with longer term plans to remain virtual in some capacity (Johns et al, 2021). It would be helpful to understand how integrated services are operating now that services conditions have changed, and how this has impacted the “one stop shop” mode of delivery which was common in many of the studies. This also feels relevant with regards to considerations about cost, as COVID-19 has increased inequality in terms of socioeconomic status, increasing psychological distress for lower status individuals or those already vulnerable (Davillas &

Jones, 2021). This means that hard to reach groups, those who were vulnerable pre-COVID, as well as young people in general whose social circumstances may have changed, may need increased or different levels of support now, and research into how services are meeting these needs is valuable.

Specific research could include comparing integrated care with standalone care – for example, by using a dataset from an earlier time point prior to implementing integrated care or from a different locality could help demonstrate whether integrated care is superior. To move this forward, Integrated Care Services for young people in NHS Trusts could consider publishing service evaluations which record not only clinical outcomes but also service user experiences, pathways to access services and treatments and waiting times. To measure cost effectiveness, Trusts may need to utilise longer term follow-up and record economic outcomes, including longer term use of health services and employment status. Some of this may be gained from the clinical record or from longer term assessments.

As well as large scale service evaluations, it is important to understand the perspectives both of service users and the views of individuals who are not accessing services. Although challenging, it feels important that individuals who may be struggling to access services still have an opportunity for their perspective to be heard and allow for development of different insights. The qualitative project demonstrates one method of achieving this, by reaching out to previous research participants. This project also demonstrates the need for longer-term research to understand how young people’s views, experiences and support needs have continued to change over the pandemic.

Reflections

Both of these papers involved working with wider study teams. I feel that this allowed me to gain valuable research experience and made my research feel more meaningful as both my papers are a part of a wider project. However, at times it felt difficult to manage the team's interests and the role for me and the requirements of my overall thesis. Had I not joined the teams, I would have had more control over my research. However, I feel joining the teams helped me learn about research in the real world, and how team structures work and can be helpful. I was lucky to be well supported by my supervisors at the UEA which enabled me to problem solve minor difficulties.

Dissemination Plans

The results of the completed papers will be shared with the wider study teams. In terms of wider dissemination, both papers have been prepared for publication. The empirical paper has been prepared for British Journal of Clinical Psychology and the systematic review has been prepared for the Early Intervention in Psychiatry Journal.

Overall Conclusion

To conclude, this thesis has found pre-COVID-19 evidence that integrated mental health and social care could improve young people's experiences of support. However, evidence was limited to support integrated care improves clinical effectiveness, and no measurement of cost effectiveness. The empirical study found in young people with pre-existing mental health difficulties, their response to the pandemic was impacted by their mental health and the pandemic further impacted their mental health. This meant that there were additional emotional stresses to manage, however experience of managing adversity supported developing coping strategies. Some of these may be helpful for practitioners working with young people to adopt, to support them in moving forward during and beyond COVID-19. Further research will support a better understanding of the longer term needs of this population, and how integrated mental health and social care may better support them.

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Appendices

Appendix A: Early Intervention in Psychiatry Author Guidelines

1. SUBMISSION

Thank you for your interest in *Early Intervention in Psychiatry*. Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at **http://mc.manuscriptcentral.com/eip**

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2. AIMS AND SCOPE

Early Intervention in Psychiatry publishes original research articles and reviews dealing with the early recognition, diagnosis and treatment across the full range of mental and substance use disorders, as well as the underlying epidemiological, biological, psychological and social mechanisms that influence the onset and early course of these disorders. The journal provides comprehensive coverage of early intervention for the full range of psychiatric disorders and mental health problems, including schizophrenia and other psychoses, mood and anxiety disorders, substance use disorders, eating disorders and personality disorders. Papers in any of the following fields are considered: diagnostic issues, psychopathology, clinical epidemiology, biological mechanisms, treatments and other forms of intervention, clinical trials, health services and economic research and mental health policy. Special features are also published, including hypotheses, controversies and snapshots of innovative service models.

In contrast with mainstream healthcare, early diagnosis and intervention has come late to the field of psychiatry. *Early Intervention in Psychiatry* creates a common forum for researchers and clinicians with an interest in the early phases of a wide range of disorders to share ideas, experience and data. This journal not only fills a gap, but also creates a new frontier in academic and clinical psychiatry.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Articles reporting original work that embodies scientific excellence in psychiatry and advances in clinical research (maximum word count for text 3000; abstract 250);

Reviews which synthesize important information on a topic of general interest to early intervention in psychiatry. (maximum word count for text 5000; abstract 250);

Brief Reports which present original research that makes a single point, or negative studies of important topics (maximum word count for text 1500; abstract 150);

Early Intervention in the Real World, a special features section which focuses on issues such as service descriptions and delivery, and clinical practice guidelines (maximum word count for text 3000; abstract 250);

Editorials or New Hypotheses. Please contact the editorial office before writing an Editorial or New Hypotheses article for the journal (maximum word count for text 1000);

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o Your co-author details, including affiliation and email address. (Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)

o Statements relating to our ethics and integrity policies, which may include any of the following (Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):

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Abbreviations. Abbreviations should be used sparingly – only where they ease the reader's task by reducing repetition of long, technical terms. Initially use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

Trade names. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name, and the name and location of the manufacturer, in parentheses.

Parts of the Manuscript

The text file should be presented in the following order:

i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's **best practice SEO tips**);
ii. A short running title of less than 40 characters;
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Abstract and keywords;
vi. Main text;
vii. Acknowledgements;
viiii. Conflict of interest statement;
ix. References;
x. Tables (each table complete with title and footnotes);
xi. Figure legends;
xii. Appendices (if relevant).

Figures and supporting information should be supplied as separate files.

Abstract and key words

All articles must have a structured abstract that states in 250 words (150 words for Brief Reports) or fewer the purpose, basic procedures, main findings and principal conclusions of the study. Divide the abstract with the headings: Aim, Methods, Results, Conclusions. The abstract should not contain abbreviations or references.

Five key words, for the purposes of indexing, should be supplied below the abstract, in alphabetical order, and should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at **http://www.nlm.nih.gov/mesh/meshhome.html**.

Text

Authors should use the following subheadings to divide the sections of their manuscript: Introduction, Methods, Results and Discussion.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

References

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one, and a DOI should be provided for all references where available.

Journal article

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, *159*, 483–486. doi:10.1176/appi.ajp.159.3.483

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from **http://www.youtube.com/watch?v=Vja83KLQXZs**

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted. **Click here** for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

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Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

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The journal adheres to the **definition of authorship as set out by The International Committee of Medical Journal Editors (ICMJE).** The ICMJE recommends that authorship be based on the following 4 criteria:

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- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

In addition to being accountable for the parts of the work he or she has done, an author should be able to identify which co-authors are responsible for specific other parts of the work. In addition, authors should have confidence in the integrity of the contributions of their co-authors. All those designated as authors should meet all four criteria for authorship, and all who meet the four criteria should be identified as authors.

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Author Guidelines updated 22 November 2021

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The following types of paper are invited:

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- theoretical papers, provided that these are sufficiently related to empirical data;
- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications;
- Brief Reports and Comments.

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Papers describing quantitative research should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). Brief reports should not exceed 2000 words and should have no more than one table or figure. Any papers that are over this word limit will be returned to the authors. Appendices are included in the word limit; however online appendices are not included.

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iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
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Author Guidelines updated 23 July 2021

Appendix C: Critical Appraisal Tables

Table 1: Effective Public Healthcare Panacea Project Quality Assessment Tool for Quantitative Studies

	Hagner et al, 1999	Dore-Gauthier et al, 2020	Harris et al, 2003	Kidd et al, 2019	Vorhies et al, 2009	Busen et al., 2007	Powell et al., 2016	Slesnick & Erdem, 2012	Ashby et al., 2019	Henderson et al., 2021
Are the individuals selected to participate in the study likely to be representative of the target population?	**Very likely**	**Very likely**	**Very likely**	**Very likely**	**Very likely**	**Very likely**	**Very likely**	**Very likely**	**Very likely**	**Very likely**
What percentage of selected individuals agreed to participate?	**80-100**	**Can't tell**	**80-100**	**80-100**	**80-100**	**Not applicable**	**80-100**	**80-100**	**80-100**	**Can't tell**
Score A	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**1**
Study Design	**Cohort - one group pre and post**	**Cohort- two groups**	**cohort analytic (audit of records)**	**Cohort - one group pre and post**	**Cohort - one group pre and post**	**Cohort analytic (audit of records)**	**Cohort- one group pre and post**	**Cohort - one group pre and post**	**Cohort- two groups**	**discrete choice experiment (DCE) survey.**
Was the study described as randomised	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**
described	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**
appropriate	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**
Score B	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**

Were there important differences between groups prior to the intervention?	**N/A**	**Different time points**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**Different time points**	**N/A**
If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?	**N/A**	**None**	**N/A**	**N/A**	**N/A**	**N/A**	**None**	**N/A**	**No**	**N/A**
Score C	**N/A**	**2**	**N/A**	**N/A**	**N/A**	**N/A**	**2**	**N/A**	**N/A**	**N/A**
Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**
Were the study participants aware of the research question?	**Can't tell**	**Can't tell**	**Can't tell**	**Can't tell**	**Can't tell**	**Can't tell**	**Can't tell**	**Can't tell**	**Can't tell**	**Yes**
Score D	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**N/A**	**1**

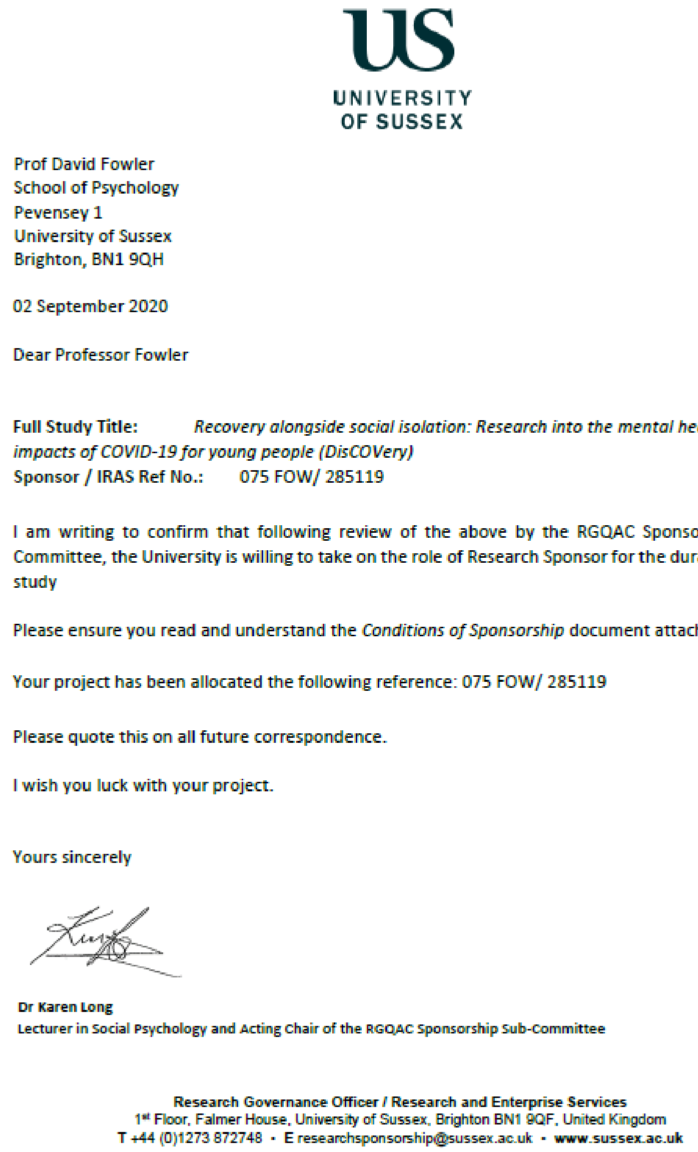
Were data collection tools shown to be valid?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**	**Can't tell**	**Yes**
Were data collection tools shown to be reliable?	**Yes**	**Yes**	**Can't tell**	**yes**	**Yes**	**No**	**Yes**	**Yes**	**Can't tell**	**Yes**
Score E	**1**	**1**	**2**	**1**	**1**	**3**	**1**	**1**	**3**	**1**
Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**N/A**	**N/A**	**Yes**	**No**	**N/A**
Indicate the percentage of participants completing the study	**80-100**	**80-100**	**N/A**	**80-100**	**80-100**	**N/A**	**80-100**	**80-100**	**Can't tell**	**N/A**
Score F	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**1**	**2**	**1**
What percentage of participants received the allocated intervention or exposure of interest?	**N/A**	**48%**	**N/A**	**N/A**	**N/A**	**80-100**	**80-100**	**N/A**	**49.17**	**N/A**

Was the consistency of the intervention measured?	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**N/A**
Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**N/A**
Indicate the unit of allocation	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**
Indicate the unit of analysis	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**	**Oorganisation**
Are the statistical methods appropriate for the study design?	**Yes**	**yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**	**Yes**	**Yes**
Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?	**Yes**	**No**	**N/A**	**Yes**	**Yes**	**No**	**can't tell**	**No**	**Yes**	**N/A**
Global rating	**Moderate**	**Moderate**	**Moderate**	**Moderate**	**Moderate**	**Weak**	**Moderate**	**Moderate**	**Moderate**	**Moderate**

Table 2: CASP Qualitative Checklist

	Van den Steene et al., 2019	**Kidd et al, 2019**	**Farr et al, 2021**
Was there a clear statement of the aims of the research?	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Mixed methods – yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Can't tell	Yes
. Has the relationship between researcher and participants been adequately considered?	Can't tell	Can't tell	Can't tell
Have ethical issues been taken into consideration?	Yes	Yes	Yes
Was the data analysis sufficiently rigorous?	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes
How valuable is the research?	Valuable as a way to understand the viewpoint of service users	Valuable to support the quantitative study	Valuable as a UK study though struggles to summarise service user and clinician perspectives; could have been two separate studies

Appendix D: Sponsor approval letter



UNIVERSITY
OF SUSSEX

Prof David Fowler
School of Psychology
Pevensey 1
University of Sussex
Brighton, BN1 9QH

02 September 2020

Dear Professor Fowler

Full Study Title: *Recovery alongside social isolation: Research into the mental health impacts of COVID-19 for young people (DisCOVery)*
Sponsor / IRAS Ref No.: 075 FOW/ 285119

I am writing to confirm that following review of the above by the RGQAC Sponsorship Sub-. Committee, the University is willing to take on the role of Research Sponsor for the duration of the study

Please ensure you read and understand the *Conditions of Sponsorship* document attached.

Your project has been allocated the following reference: 075 FOW/ 285119

Please quote this on all future correspondence.

I wish you luck with your project.

Yours sincerely

Dr Karen Long
Lecturer in Social Psychology and Acting Chair of the RGQAC Sponsorship Sub-Committee

Research Governance Officer / Research and Enterprise Services
1st Floor, Falmer House, University of Sussex, Brighton BN1 9QF, United Kingdom
T +44 (0)1273 872748 • E researchsponsorship@sussex.ac.uk • **www.sussex.ac.uk**

Appendix D: Letter of Access

A member of:
Association of UK University Hospitals

Sussex Partnership
NHS Foundation Trust

Research and Development
Sussex Education Centre
Mill View Hospital
Nevill Avenue
Hove BN3 7HZ

Tel: 01273 265896
www.sussexpartnership.nhs.uk

22 April 2021

Dear Jennifer Keane,

Letter of access for research
IRAS: 285119
Study Title: DisCOVery

This letter confirms your right of access to conduct research through Sussex Partnership NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on **22 April 2021** and ends on **30 September 2022** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Sussex Partnership NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Sussex Partnership NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Sussex Partnership NHS Foundation Trust, you will remain accountable to your employer **Cambridgeshire and Peterborough NHS Foundation Trust** but you are required to follow the reasonable instructions of **Dr David Fowler** in this NHS organisation or those given on his behalf in relation to the terms of this right of access.

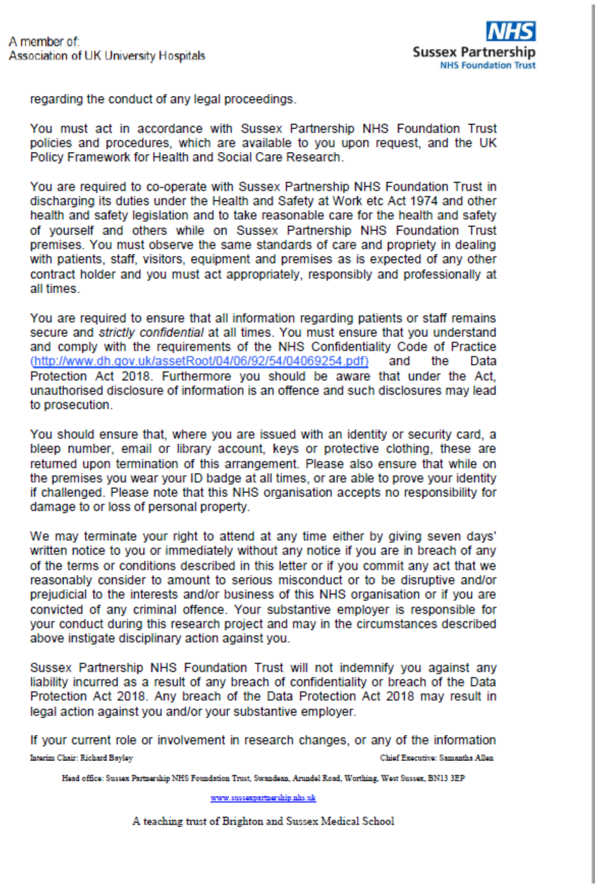
Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required

Interim Chair: Richard Bayley Chief Executive: Samantha Allen

Head office: Sussex Partnership NHS Foundation Trust, Swandean, Arundel Road, Worthing, West Sussex, BN13 3EP

www.sussexpartnership.nhs.uk

A teaching trust of Brighton and Sussex Medical School



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Sussex Partnership
NHS Foundation Trust

regarding the conduct of any legal proceedings.

You must act in accordance with Sussex Partnership NHS Foundation Trust policies and procedures, which are available to you upon request, and the UK Policy Framework for Health and Social Care Research.

You are required to co-operate with Sussex Partnership NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Sussex Partnership NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 2018. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Sussex Partnership NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information

Interim Chair: Richard Bayley Chief Executive: Samantha Allen

Head office: Sussex Partnership NHS Foundation Trust, Swandean, Arundel Road, Worthing, West Sussex, BN13 3EP

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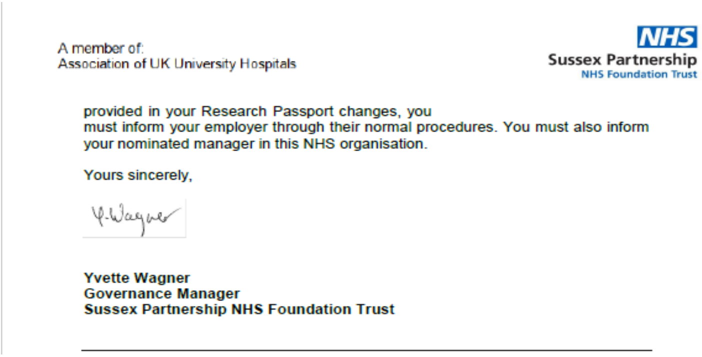


A member of:
Association of UK University Hospitals

Sussex Partnership
NHS Foundation Trust

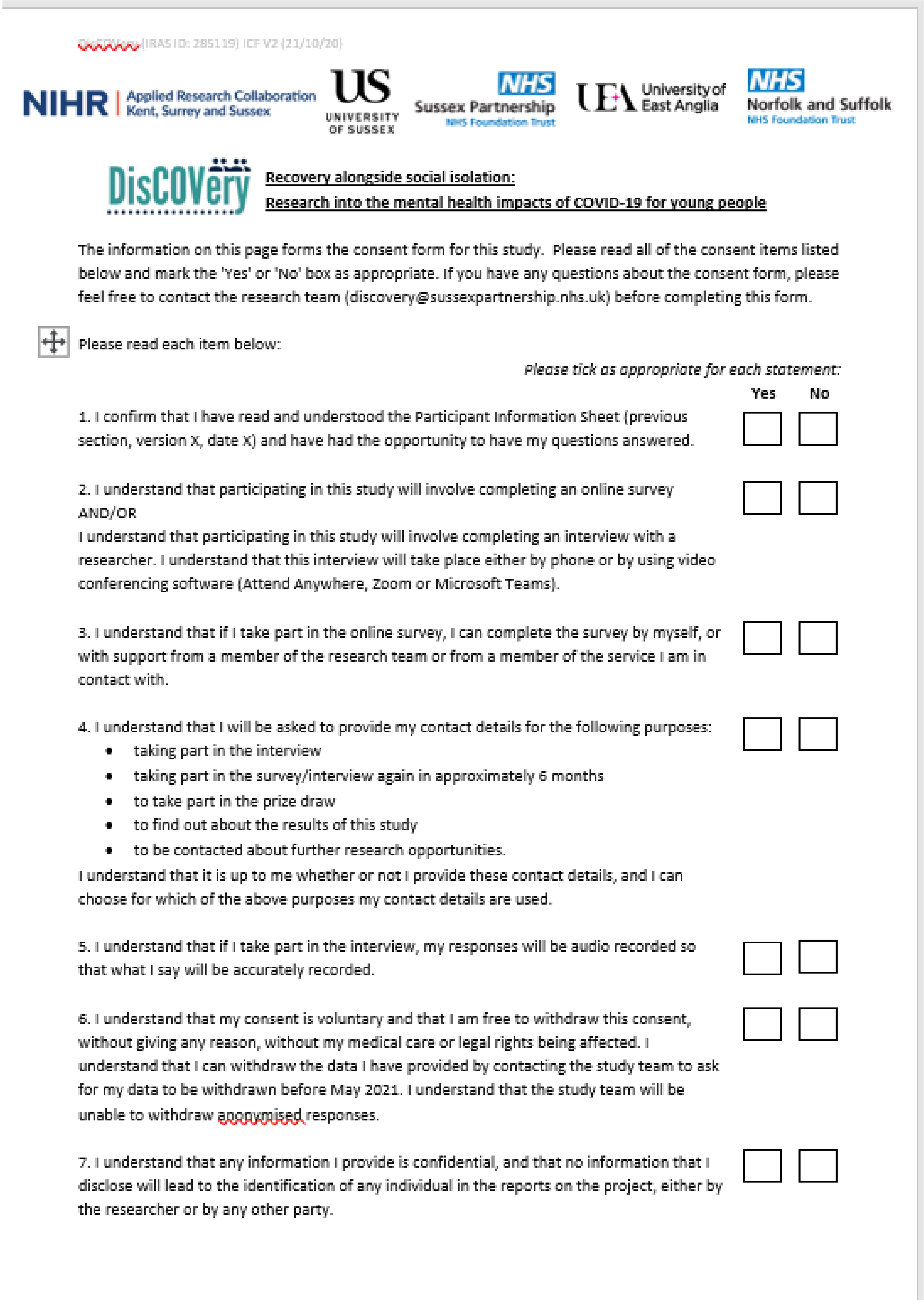
provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely,

Y.Wagner

Yvette Wagner
Governance Manager
Sussex Partnership NHS Foundation Trust

Appendix F: Participant Consent Form



DisCOVery (IRAS ID: 285119) ICF V2 (21/10/20)

NIHR | Applied Research Collaboration Kent, Surrey and Sussex
US UNIVERSITY OF SUSSEX
NHS Sussex Partnership NHS Foundation Trust
UEA University of East Anglia
NHS Norfolk and Suffolk NHS Foundation Trust

DisCOVery

Recovery alongside social isolation:
Research into the mental health impacts of COVID-19 for young people

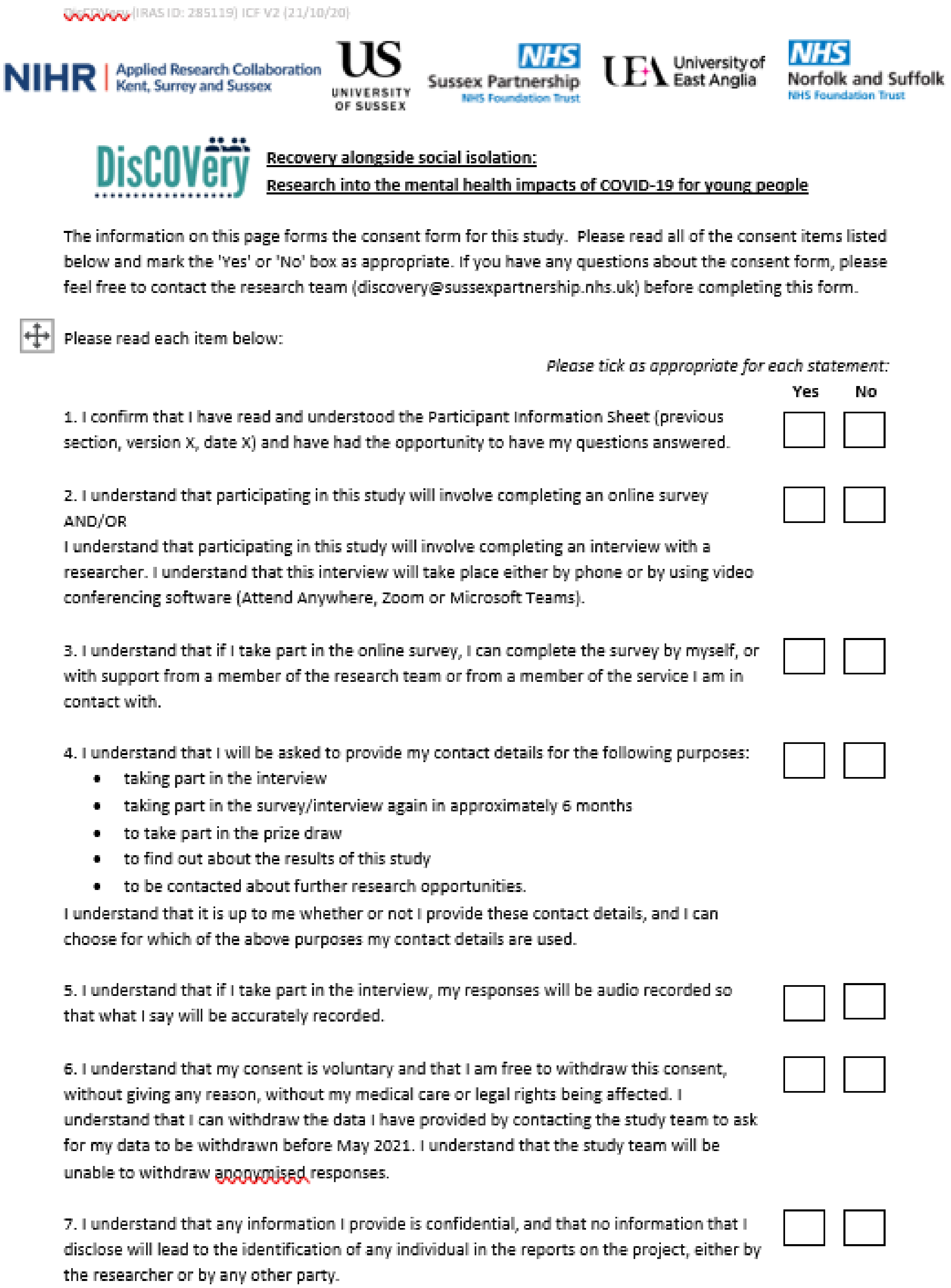
The information on this page forms the consent form for this study. Please read all of the consent items listed below and mark the 'Yes' or 'No' box as appropriate. If you have any questions about the consent form, please feel free to contact the research team (discovery@sussexpartnership.nhs.uk) before completing this form.

Please read each item below:

Please tick as appropriate for each statement:

	Yes	No
1. I confirm that I have read and understood the Participant Information Sheet (previous section, version X, date X) and have had the opportunity to have my questions answered.	☐	☐
2. I understand that participating in this study will involve completing an online survey AND/OR I understand that participating in this study will involve completing an interview with a researcher. I understand that this interview will take place either by phone or by using video conferencing software (Attend Anywhere, Zoom or Microsoft Teams).	☐	☐
3. I understand that if I take part in the online survey, I can complete the survey by myself, or with support from a member of the research team or from a member of the service I am in contact with.	☐	☐
4. I understand that I will be asked to provide my contact details for the following purposes: • taking part in the interview • taking part in the survey/interview again in approximately 6 months • to take part in the prize draw • to find out about the results of this study • to be contacted about further research opportunities. I understand that it is up to me whether or not I provide these contact details, and I can choose for which of the above purposes my contact details are used.	☐	☐
5. I understand that if I take part in the interview, my responses will be audio recorded so that what I say will be accurately recorded.	☐	☐
6. I understand that my consent is voluntary and that I am free to withdraw this consent, without giving any reason, without my medical care or legal rights being affected. I understand that I can withdraw the data I have provided by contacting the study team to ask for my data to be withdrawn before May 2021. I understand that the study team will be unable to withdraw anonymised responses.	☐	☐
7. I understand that any information I provide is confidential, and that no information that I disclose will lead to the identification of any individual in the reports on the project, either by the researcher or by any other party.	☐	☐

Experiences of young people living with mental health difficulties in the context of COVID-19 and the role of integrated social care and mental health services in providing support



DisCOVery (IRAS ID: 285119) ICF V2 (21/10/20)

NIHR | Applied Research Collaboration Kent, Surrey and Sussex

US UNIVERSITY OF SUSSEX

NHS Sussex Partnership NHS Foundation Trust

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DisCOVery

Recovery alongside social isolation:

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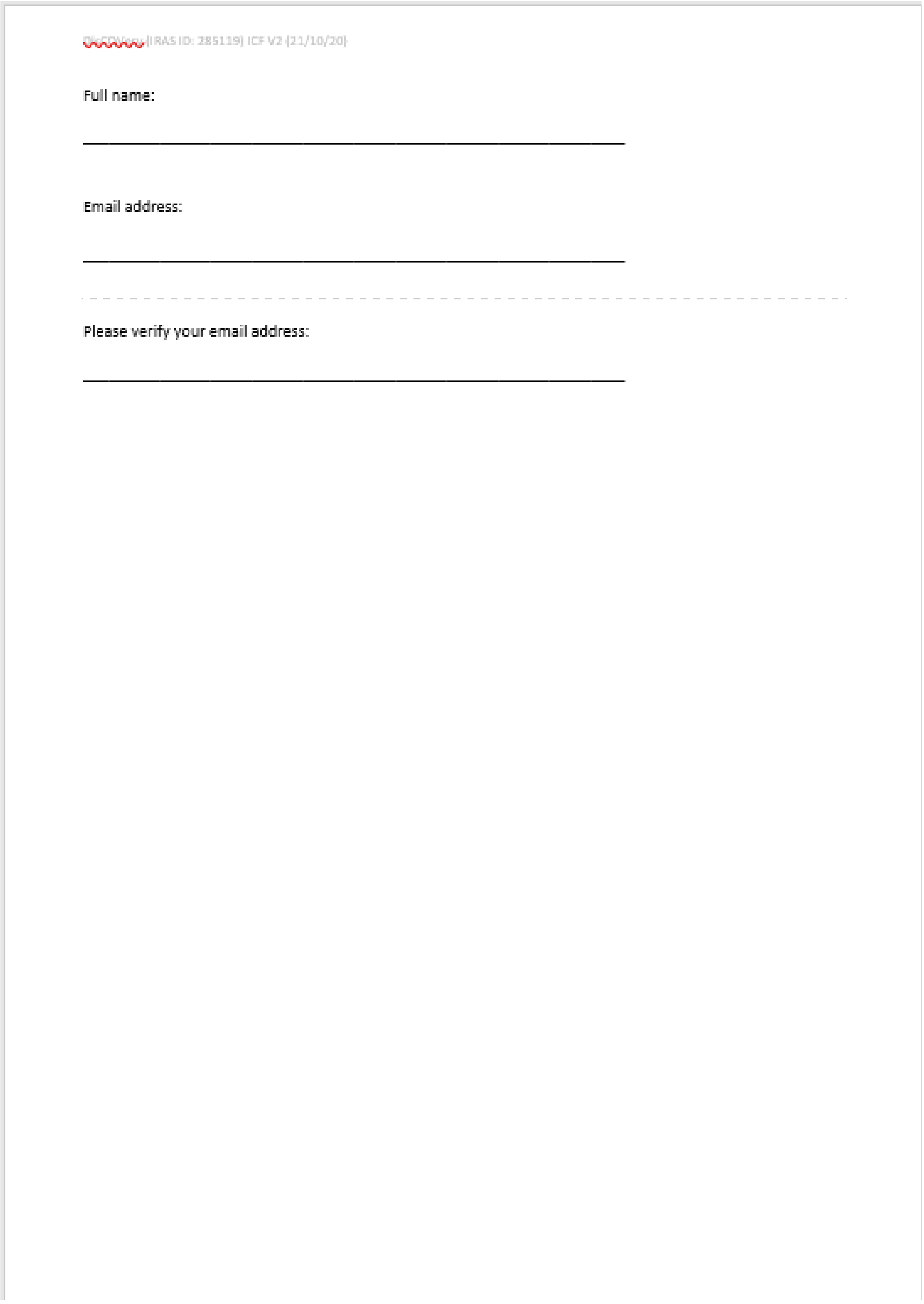


OkCOVery (IRAS ID: 285119) ICF V2 (21/10/20)

Full name:

____

Email address:

____

Please verify your email address:

____

Appendix G: Demographics / Questionnaire

This section will ask you questions about yourself and your background.

How did you hear about this study?

○ Please type the name of the service or organisation in the box (or choose from one of the listed options below) (1)
____

○ Worthing - Find It Out+ (2)

○ Hastings - iRock (4)

○ Hastings - NHS Children and Adolescent Mental Health Service (CAMHS) (5)

Page Break

Age
1. How old are you?

____

Page Break

Gender 2. Please indicate your gender:

○ Non-binary (1)

○ Female (2)

○ Male (3)

○ Other (4) ____

○ Prefer not to say (5)

Page Break

Ethnicity 3. Which ethnic group do you belong to?

- ○ White British (1)
- ○ White Other (2) ____
- ○ Chinese/Chinese British (3)
- ○ Black/African/Caribbean/Black British (4)
- ○ Asian/Asian British (5)
- ○ Mixed Ethnicity (6)
- ○ Other (8) ____
- ○ Prefer not to say (9)

Page Break

UKCitizen 4. Are you a UK citizen?

- ○ Yes (1)
- ○ No (2)

Page Break

Continent 4.1 Which continent are you from?

○ Africa (1)

○ Asia (2)

○ Australasia (3)

○ Europe (4)

○ North America (5)

○ South America (6)

Page Break

X→

English_1st 5. Is English your first language?

○ Yes (1)

○ No (2)

Page Break

X→

Current_Living 6. Who do you currently live with? *Please select all that apply.*

☐ No one, I live on my own (1)

☐ Friends/Flatmates (2)

☐ Partner/Spouse (3)

☐ Family, including parents, siblings, carers and grandparents (4)

☐ Group accommodation or hostel (including student halls of residence) (5)

☐ Homeless (6)

☐ Other (7)

Page Break

SexualOrientation 7. What term best describes your sexual orientation?

○ Asexual (1)

○ Bi/bisexual (3)

○ Gay man (4)

○ Gay woman/lesbian (5)

○ Heterosexual/straight (6)

○ Queer (7)

○ Other (8) ____

○ Prefer not to say (9)

Page Break

Highest_Qual 8. What is the highest academic qualification you have obtained?

○ No qualifications (1)

○ GCSE/O-Level/CSE or equivalent (2)

○ Completed post-16 vocational course (7)

○ A-Levels or equivalent (e.g. International Baccalaureate, Scottish higher or Advanced higher) (3)

○ National vocational qualification (NVQ or SVQ) (8)

○ BTEC (9)

○ Apprenticeship (10)

○ Undergraduate/ Bachelor's degree (BSc, BA, LLB) or equivalent (4)

○ Professional qualification (e.g. teacher training, legal practice course, chartered accountancy) (11)

○ Master's degree (MSc, MA) or equivalent (5)

○ Doctoral degree (PhD/DPhil) or equivalent (6)

Page Break

Work_Status 9. How would you describe your education or employment activity/ies immediately before the current COVID-19 pandemic?

- ○ Student - in school/college (1)
- ○ Student - at university (2)
- ○ Student - at FE college (3)
- ○ In training (4)
- ○ Self employed (5)
- ○ In part-time employment (6)
- ○ In full-time employment (7)
- ○ Unable to work due to disability (8)
- ○ Homemaker/full-time parent (9)
- ○ Currently not working or studying (10)

Page Break

Work_Status_change 10. Has your current education or employment activity/ies changed since the current COVID-19 pandemic began?

- ○ Yes (1)
- ○ No (2)

Page Break

Work_Change_Details 10.1. How has your current education or employment activity changed since the COVID-19 pandemic began? *Please select all that apply.*

○ Recently unemployed due to COVID-19 (1)

○ Furloughed due to COVID-19 (2)

○ Working from home due to COVID-19 (3)

○ Employment role has changed substantially due to COVID-19 (4)

○ Gained new employment (5)

○ Enrolled in new training or study (6)

○ Training or studying has stopped (including school is closed) (7)

○ Training or studying has changed to be online (8)

○ Other, please explain (9) ____

Page Break

Work_Industry 11. If you are, or have been working since the lockdown, what industry do you work in?

- ○ Accommodation and food services (1)
- ○ Administrative activities (2)
- ○ Agriculture, forestry and fishing (3)
- ○ Arts and entertainment (4)
- ○ Construction (5)
- ○ Education (6)
- ○ Electricity and gas (7)
- ○ Finance and insurance (8)
- ○ Health and social work (9)
- ○ Information and communication (10)
- ○ Manufacturing (11)
- ○ Mining (12)
- ○ Professional, scientific and technical activities (13)
- ○ Public administration and defence (14)
- ○ Transportation and storage (15)
- ○ Water supply and sewerage (16)
- ○ Wholesale and retail trade (17)
- ○ Other industry, not listed (18)

Page Break

Postcode 12. What is the first part of the postcode of your primary residence?

____

Page Break

Thank you. Please click next to submit your responses.

End of Block: Qualtrics PIS, ICF & Shortened Demographic Questions - qualitative only

Appendix H: Interview Schedule

Recovery alongside social isolation: Research into the mental health impacts of COVID-19 for young people

Interview Schedule

Introduction: "The aim of this interview is to get an understanding of your experiences of the COVID-19 pandemic.
This interview will take about an hour. We're interested in learning about your personal viewpoint, so there are no right or wrong answers. Please just talk about your experiences in as much detail as you feel comfortable sharing. If there are any questions that you feel that you don't want to answer or are unable to answer, please let me know and we can move on. It is also fine for you to ask to end this interview at any time.
Do you have any questions before we get started?"

Note: Questions are in the context of current restrictions, specific to the interviewee e.g. national lockdown/level of tier system for participant's area.

Background

1. Can you start by telling me about how things were going for you shortly before the coronavirus outbreak in the UK?
   Prompts as needed:
   - *How were you getting on at school/college/work?*
   - *How were you getting on with your family and friends?*
   - *What sorts of things were you doing in your free time?*
   - *How were you spending a typical week day? Weekend?*

2. How would you describe your mental and physical health during the period before the first national lockdown (starting March 23rd 2020)?
   Prompts as needed:
   - *What involvement, if any, did you have with health services?*
   - *Can you think of anything else from the time before lockdown that was particularly beneficial – or possibly detrimental – to your mental and physical health?*

Direct effects

3. Can you tell me your thoughts about coronavirus?
   Prompts as needed:

- *In what ways, if any, are you concerned for yourself/for other individuals/for wider society?*
- *Have these concerns changed since the start of the pandemic?*

Getting coronavirus:

4. Do you ever think about you or someone else getting coronavirus?
   Have you ever been tested, or thought about getting tested, for coronavirus?
   Prompts as needed:
   - *How much, if at all, do you think thinking about you or someone else getting coronavirus has affected you?*

Restrictions:

5. What effects, if any, do current restrictions have on your relationships with family/other people in your household? What difference, if any, has this made to your mental health?

6. What effects, if any, do current restrictions have on your relationships with friends/social groups/people you care about?
   Prompts as needed:
   - *How often are you in contact with friends or people you care about but don't live with?*
   - *What sorts of things do you communicate about?*
   - *How do you spend time together?*
   - *How does this compare with before current restrictions (eased/stricter)*
   - *Have your friendships and social groups changed in any other ways?*
   - *What difference, if any, has this made to your mental health?*

7. What effect, if any, do current restrictions have on your ability to take part in physical activity?
   Prompts as needed:
   - *What impact, if any, has this had on your physical health?*
   - *What impact, if any, has this had on your mental health?*

8. Overall, what would you say are the most stressful, or challenging, aspects of current restrictions ?
   Prompts as needed:
   - *How do you cope with these (e.g., by seeking formal/informal help/self-management)?*
   - *What differences do these make, if any?*

9. Is there anything positive about the current restrictions , that you would like stay the same?

Indirect effects and long-term consequences

10. How often are you in contact with services (e.g. mental health/education/social care/voluntary sector), and what for?
    Prompts as needed:
    - *How does this compare with before the first lockdown?*
    - *Changes in current restrictions?*

11. Have changes in service contact made any difference to your health?
    Prompts as needed:
    - *What about now that restrictions have eased/become stricter?*

12. Can you tell me about your local community?
    Prompts as needed:
    - *Are there any clubs or local services that you have contact with?*
    - *Are there any clubs or local services that are helpful/not helpful during this time?*
    - *Are there any other ways that you think your local community could support you during this time?*
    - *Is there anything that you find positive/not positive in your local community during this time?*

13. What else, positive or negative, has changed in your life due to current restrictions? (e.g., with relationships at home, friendships and social groups, education/work). What effects, if any, have these changes had on your mental health in particular?

14. How much do you think the experience of coronavirus and the restrictions has affected you compared with other people your age?
    Prompts as needed:
    - *In what ways, if any, has it changed you as a person?*
    - *What have you discovered, if anything, about yourself since the outbreak began?*
    - *Have you thought about how you might have managed this situation differently given the experiences that you had?*

15. What do you expect your life to be like in a year?

16. What do you hope your life will be like in a year?
    Prompts as needed:
    - *What goals, if any, did you have for yourself and your future before the outbreak?*
    - *How has the experience of recent months affected your hopes and goals for the future?*
    - *Do you have any fears about what your life could be like in a year?*

17. Thinking about current restrictions, what kind of help/support/information do you think is most needed (e.g., around work/education)?
    Prompts as needed:
    - *Who would you be most likely to ask for this help, support or information if you needed it?*

18. Based on your experiences:

a. If you could send one important message to others your age to help them during this period, or a warning about something that doesn’t help, what would you say?
b. If you could send one important message to services about how best to support young people during this period , what would you say?

Wrapping up

- Is there anything you’d like to say that we haven’t mentioned yet?
- How have you found taking part in this interview?
- Check: interest in receiving summary of results

Appendix I: Debrief Sheet

Thank you for taking part in the Recovery alongside social isolation: Research into the mental health impacts of COVID-19 for young people study.

Your responses are really valued and the information collected will help us and other people understand more about how to best support individuals and communities throughout and beyond the COVID-19 pandemic.

We appreciate that responding may have been difficult. Please speak to someone if you are having any difficulties with your mental health or wellbeing. There is lots of support available.

Some support options:

- Speak to your GP and/or current care team about any support needs you may have
- *NHS Direct* (24 hour help and guidance) 111
- *Samaritans* (24 hour help and support) Call: 116 123 / Email: jo@samaritans.org
- *Saneline Helpline* (4.30pm-10.30pm help and support) 0300 304 7000
- *Hopeline UK* (under 35s only) Call: 0800 068 4141 / Email: pat@papyrus-uk.org
  - Monday-Friday: 9am – 10pm
  - Weekends: 2pm – 10pm
  - Bank holidays: 2pm – 10pm
- *Mind Infoline* (Mon- Fri 9am-6pm – closed bank holidays) 0300 123 3393

You can always phone emergency services on 999 or visit your nearest A&E if you are feeling very distressed or unable to keep yourself safe. Alternatively, speak to a trusted friend/family member and ask them to help you make contact with any of the above services if that might be helpful. We would like to encourage you to make of a note of the sources of support outlined on this page (e.g., print, take a screen shot of).

Next Steps…

If you shared your contact details with us, you will now only be contacted in the ways you indicated you wanted us to use your details.

Prize draw: If you have taken part in the survey and opted to be entered into the prize draw, you will now be in with the chance of winning £25 in vouchers. One winner will be selected at random and then contacted via email or telephone

General Study Results: If you opted to receive the study results, once the results are ready these will be sent to the email address you provided. If you provided your telephone number we will contact you to find out how you would like the results to be sent you.

Interview: If you indicated that you would be interested in taking part in the informal interview, and you have not yet taken part, you may be contacted via email or telephone about this opportunity. We will only be completing the interview with a small number of people, so we may not be able to contact everyone that is interested. If you are contacted you will be given more information to help you decide whether it is something you would like to participate in. If you decide to take part you would receive £5 in vouchers.

Follow up survey and/or interview: If you indicated that you would be interested in taking part in a follow up survey and/or interview and would be happy for us to contact you about this opportunity, you will be contacted via email or telephone in approximately 6 months' time. You will be given up to date information to help you decide whether it is something you would like to participate in again at that time.

Contacts for further information…

If you have any questions or need further information about this specific project, you can contact the research team at any time using the following email addresses:

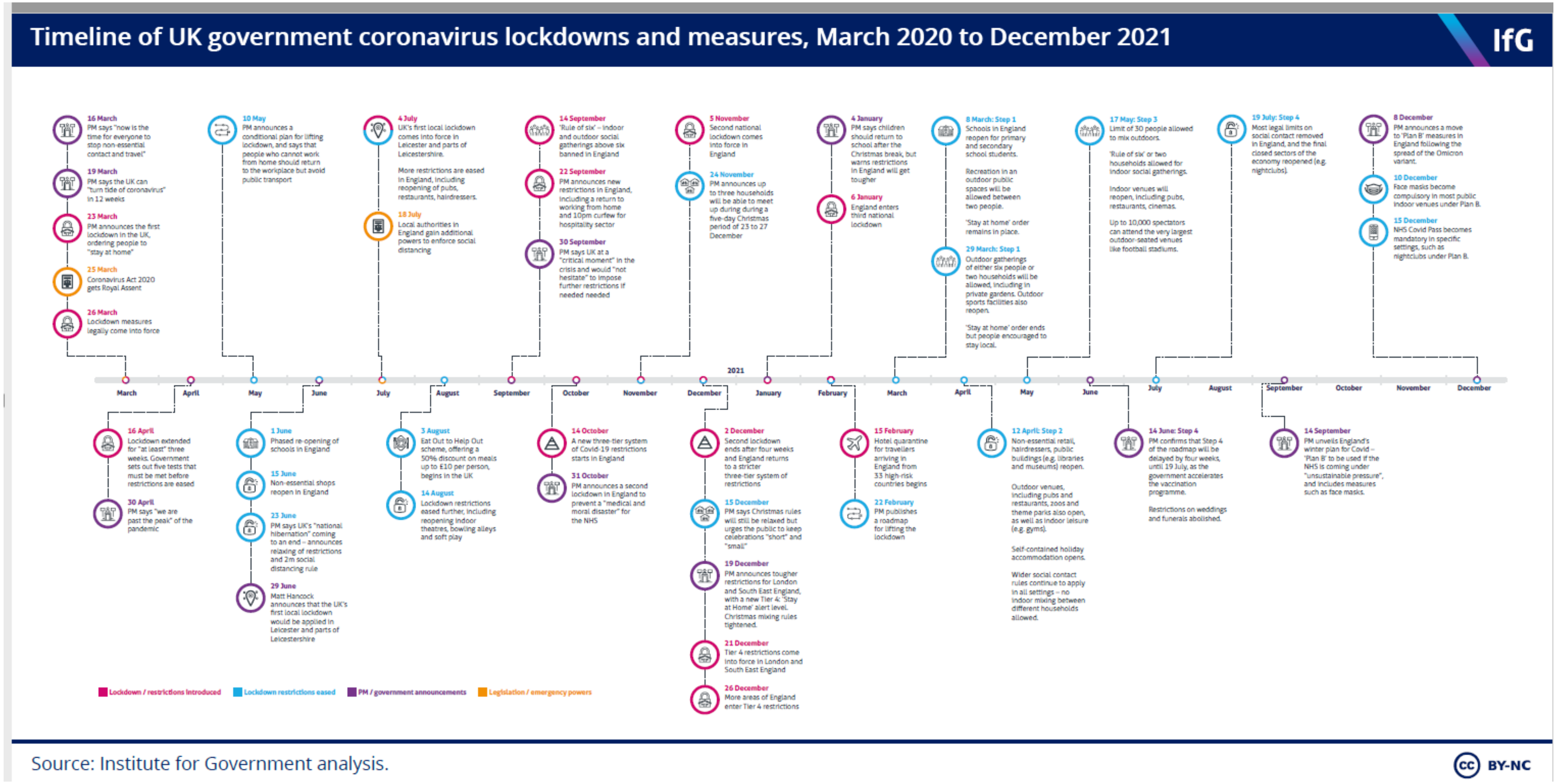
- discovery@sussexpartnership.nhs.uk

If you would like to speak to the University of Sussex research sponsorship team, please use the following email address:

- researchsponsorship@sussex.ac.uk

Thank you for taking the time to participate

Appendix J: COVID key dates table



Timeline of UK government coronavirus lockdowns and measures, March 2020 to December 2021

16 March
PM says "now is the time for everyone to stop non-essential contact and travel"

19 March
PM says the UK can "turn tide of coronavirus" in 12 weeks

23 March
PM announces the first lockdown in the UK, ordering people to "stay at home"

25 March
Coronavirus Act 2020 gets Royal Assent

26 March
Lockdown measures legally come into force

16 April
Lockdown extended for "at least" three weeks. Government sets out five tests that must be met before restrictions are eased

30 April
PM says "we are past the peak" of the pandemic

10 May
PM announces a conditional plan for lifting lockdown, and says that people who cannot work from home should return to the workplace but avoid public transport

1 June
Phased re-opening of schools in England

15 June
Non-essential shops reopen in England

23 June
PM says UK's "national hibernation" coming to an end – announces relaxing of restrictions and 2m social distancing rule

29 June
Matt Hancock announces that the UK's first local lockdown would be applied in Leicester and parts of Leicestershire

4 July
UK's first local lockdown comes into force in Leicester and parts of Leicestershire.

More restrictions are eased in England, including reopening of pubs, restaurants, hairdressers.

18 July
Local authorities in England gain additional powers to enforce social distancing

3 August
Eat Out to Help Out scheme, offering a 50% discount on meals up to £10 per person, begins in the UK

14 August
Lockdown restrictions eased further, including reopening indoor theatres, bowling alleys and soft play

14 September
'Rule of six' – indoor and outdoor social gatherings above six banned in England

22 September
PM announces new restrictions in England, including a return to working from home and 10pm curfew for hospitality sector

30 September
PM says UK at a "critical moment" in the crisis and would "not hesitate" to impose further restrictions if needed needed

14 October
A new three-tier system of Covid-19 restrictions starts in England

31 October
PM announces a second lockdown in England to prevent a "medical and moral disaster" for the NHS

5 November
Second national lockdown comes into force in England

24 November
PM announces up to three households will be able to meet up during during a five-day Christmas period of 23 to 27 December

2 December
Second lockdown ends after four weeks and England returns to a stricter three-tier system of restrictions

15 December
PM says Christmas rules will still be relaxed but urges the public to keep celebrations "short" and "small"

19 December
PM announces tougher restrictions for London and South East England, with a new Tier 4: 'Stay at Home' alert level. Christmas mixing rules tightened.

21 December
Tier 4 restrictions come into force in London and South East England

26 December
More areas of England enter Tier 4 restrictions

4 January
PM says children should return to school after the Christmas break, but warns restrictions in England will get tougher

6 January
England enters third national lockdown

15 February
Hotel quarantine for travellers arriving in England from 33 high-risk countries begins

22 February
PM publishes a roadmap for lifting the lockdown

8 March: Step 1
Schools in England reopen for primary and secondary school students.

Recreation in an outdoor public spaces will be allowed between two people.

'Stay at home' order remains in place.

29 March: Step 1
Outdoor gatherings of either six people or two households will be allowed, including in private gardens. Outdoor sports facilities also reopen.

'Stay at home' order ends but people encouraged to stay local.

12 April: Step 2
Non-essential retail, hairdressers, public buildings (e.g. libraries and museums) reopen.

Outdoor venues, including pubs and restaurants, zoos and theme parks also open, as well as indoor leisure (e.g. gyms).

Self-contained holiday accommodation opens.

Wider social contact rules continue to apply in all settings – no indoor mixing between different households allowed.

17 May: Step 3
Limit of 30 people allowed to mix outdoors.

'Rule of six' or two households allowed for indoor social gatherings.

Indoor venues will reopen, including pubs, restaurants, cinemas.

Up to 10,000 spectators can attend the very largest outdoor-seated venues like football stadiums.

14 June: Step 4
PM confirms that Step 4 of the roadmap will be delayed by four weeks, until 19 July, as the government accelerates the vaccination programme.

Restrictions on weddings and funerals abolished.

19 July: Step 4
Most legal limits on social contact removed in England, and the final closed sectors of the economy reopened (e.g. nightclubs).

14 September
PM unveils England's winter plan for Covid – 'Plan B' to be used if the NHS is coming under "unsustainable pressure", and includes measures such as face masks.

8 December
PM announces a move to 'Plan B' measures in England following the spread of the Omicron variant.

10 December
Face masks become compulsory in most public indoor venues under Plan B.

15 December
NHS Covid Pass becomes mandatory in specific settings, such as nightclubs under Plan B.

🟥 Lockdown / restrictions introduced
🟦 Lockdown restrictions eased
🟪 PM / government announcements
🟧 Legislation / emergency powers

Source: Institute for Government analysis.

Accessed from: https://www.instituteforgovernment.org.uk/sites/default/files/timeline-coronavirus-lockdown-december-2021.pdf