The experience of the COVID pandemic for people with Congenital Heart Disease (CHD) in the U.K.

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ABSTRACT

Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2, referred to as COVID-19 in this paper) is a novel coronavirus first discovered in Wuhan, China (Tan & Aboulhosn, 2020). Since it's discovery it has spread across the world and as of 8th May there have been 156,496,592 confirmed cases of COVID around the world with 3,264,142 confirmed deaths (WHO, 2021). Current literature suggests the pandemic and subsequent government responses have had a significant impact on the global population with rises in mental health difficulties, poorer physical health, relationship difficulties and changes to people's work lives. Despite an awareness of people with chronic illnesses being at greater risk of severe illness and death from covid-19, there is minimal research on how the pandemic has impacted this group, and even less on how it has affected people with specific types of chronic illness such as epilepsy or congenital heart disease (CHD).

Due to these identified gaps in the literature, this study focussed on the experiences of people with CHD during the pandemic in the U.K. Informed by critical realist epistemology and using qualitative methodology nine participants took part in semi-structured interviews to gather information on how their lives had been impacted by the current pandemic. Ages ranged from 32 to 54 years and the sample consisted of seven women and two men.

Using inductive thematic analysis three themes were constructed from the data; 'vulnerability', 'wellbeing' and 'staying connected'. Similarly, to existing research, participants identified difficulties in their mental wellbeing, changes in their physical health and difficulties in relationships and work. Difficulties experienced by being labelled as vulnerable, being in the shielding group or not, narratives from others as 'burdensome' and significant lifestyle changes were raised and add to the existing literature. Recommendations for further research and improvements to government policy and guidelines are made.

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I would like to dedicate this thesis to my daughter Emmeline Russ. Thank you for making me smile, making me laugh, keeping me humble and motivating me to be better.

Contents

1 INTRODUCTION

1.1 Overview

This chapter begins by defining COVID-19 and reviewing the general impact of the pandemic across the world. The chapter then focusses on literature investigating the impact the pandemic has had on people's daily lives, including their physical and mental health, work, and relationships. A case will then be made for why it is important to understand the experiences of the pandemic for those with chronic illnesses and a scoping review will be conducted to review the literature already available on this topic. A critique of the literature is made which leads to the specific rationale, aims and research questions of the present study.

1.2 COVID-19

Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2, referred to as COVID-19 in this paper) is a novel coronavirus first discovered in Wuhan, China (Tan & Aboulhosn, 2020). It is most commonly characterised by a fever, dry cough and shortness of breath and due to an incubation period of approximately 5.1 days, it is thought to spread through mainly asymptomatic carriers, making the disease difficult to contain (Mungomklang et al., 2021). The World Health Organisation (WHO) declared a global pandemic on 11th March 2020 and due to the lack of preventative or effective medical treatments for COVID-19, as well as its high transmission rate, world governments, in agreement with WHO, implemented social distancing guidance in addition to hygiene (Kalron et al., 2021). These guidelines also helped prevent healthcare systems from collapsing from the additional stress of pandemic related illness. The UK government introduced guidance for all but essential workers to stay at home and isolate from people outside of their households on March 23rd 2020 (National Audit Office, 2021). Since then, the UK has experienced two further lockdowns as cases of COVID-19 have surged.

As of 8th May 2021 there have been 156,496,592 confirmed cases of COVID around the world with 3,264,142 confirmed deaths (WHO, 2021). On the same date within the United Kingdom 4,431,047 confirmed cases have been recorded with 127,598 deaths. Data from those infected has shown that COVID-19 is more severe and more fatal in the elderly and those with underlying health conditions such as diabetes, heart conditions and cardiovascular diseases (Yange et al., 2020).

It is also important to highlight the unequal impact COVID-19 has had across the population. Historically, pandemics have often led to worse outcomes for marginalised groups (Ahmed et al., 2020). In the current pandemic, research has shown that ethnic minorities, the socio-economically disadvantaged and the elderly are at greater risk of severe infection and death from COVID-19. In the U.K. the mortality rates from COVID-19 for those in deprived areas was more than double that of non-deprived areas and for Black, Asian, and Minority Ethnic groups, mortality rates were up to four times higher for certain groups (Public Health

England, 2020). These differences are not widely reported with the media and government reporting aggregate data rather than separating cases by socio-demographic groups.

Several reasons for these disparities have been suggested including the increased likelihood people in these groups work in roles that cannot be done from home. Data suggests those in lowest income houses were six-times less likely to be able to do this (Atchison et al., 2020). Additionally, people in these groups are more likely to have chronic illnesses due to persistent structural and social inequalities (Shadmi, 2013) making them more vulnerable to severe illness and death. A third reason given by Ali et al., (2020) is the 'one size fits all' approach to public health, which means that misconceptions and misinformation around COVID-19, particularly in ethnic minorities (see Laurencin & McClinton, 2020) have been largely ignored with health messages focussing on hand hygiene rather than attempting to dispel these myths. It is also important to consider that government responses to the pandemic may also compound the issue, for example, school closures can increase food insecurity for children living in poverty and malnutrition can lead to a lowering of people's immune responses placing these children at greater risk from COVID-19 infection (Abrams & Szefler, 2020).

1.3 The Wider impact of COVID-19

The World Food Program predicts that by the end of 2020, 265 million people will be experiencing food insecurity, an increase from the 135 million before the pandemic began (Food Security Information Network, 2020). Issues with food supply chains and food production, increase in food prices as well as a reduction in income have led to issues with food security (World Bank, 2020). Food insecurity has also been found in developed countries with a study in the USA noting a 2% increase in food insufficiency in their sample (Nagata et al., 2021)

Whilst the long-term impact of COVID-19 on the economy remains an unknown, historical evidence from prior pandemics suggests that individuals will be impacted directly due to poorer health and indirectly due to less investment in human capital (Arthi & Parman, 2021). Also, the unknown long-term effects of COVID for survivors is an important factor as well as the pandemic-related slowing of the economy, all of which are likely to last for generations. Poor health reduces people's labour market prospects which lead to poorer health outcomes, meaning that safety nets for these people with poorer economic outcomes and chronic health issues will be important.

With data showing a large impact worldwide, a greater understanding of what that means in terms of change for people's daily lives is important, especially for planning and preparation for future pandemics. When considering these changes, it is also important to note government responses and policies such as lockdowns, quarantining, and what impact health safety behaviours such as social distancing have had. Research into the impact of

COVID-19 at present can be delineated into the following broad themes outlined below: physical health, mental health, employment, and relationships.

1.4 Physical health

Literature on people's physical health behaviours includes drinking, smoking, diet, and exercise. Previous studies have shown that people can often use food as a coping mechanism, eating more or higher calorie foods at times of stress (Buckland et al., 2021). Eating more calories than needed, can lead to obesity which is a known risk factor for several health complications including an increased risk of severe and fatal COVID-19 complications. Given the pandemic may cause high levels of stress, understanding people's eating behaviours and how they have been impacted is important. Studies have found up to half of participants reporting their diet worsening over lockdowns and during the pandemic (Poelman et al., 2020; Coulthard et al., 2021; Quaresma et al., 2021; Al-Domi et al., 2021). In participants whose diet worsened, increased appetite, weight gain and increased snacking was also reported (Al-Domi et al., 2021). Anxiety regarding COVID-19 and maladaptive coping strategies (such as self-blame and low acceptance) were associated with uncontrolled eating during lockdown (Coulthard et al., 2021).

1.5 Addictive Behaviours

Further to an increase in eating and snacking, Finlay and Gilmore (2020) noted that although supermarket sales in March increased by 43% as people began to stock up on store cupboard food, sales of alcohol increased by 67%. Although it is unclear whether this increase in alcohol purchase was to make up for the closure of pubs and restaurants, research has since shown that 17% and 34.7% of participants self-reported an increase in their alcohol use in respective studies (Jacob et al., 2020; Koopmann et al., 2020; Neill et al., 2020). Significant factors linked to an increase in alcohol consumption included job loss, eating a lot more than usual, sleeping significantly more or less and higher levels of depression and stress (but not anxiety) predicted an increase in drinking. Women were found to drink more than men which was suggested to be because of the pressures on families during lockdown to home-school children whilst continuing to work full-time, a burden hypothesised by the authors to fall largely on mothers (Neill et al., 2020). Chappuy et al., (2021) also found increases in other addictive behaviours including heroin and behavioural addictions (such as gambling and pornography).

1.6 Physical Activity

Physical activity is another area of literature into COVID-19 and its impact as it is important for achieving good health. Exercise has been shown to have a beneficial effect on immune function, can prevent and treat a variety of chronic illnesses, has benefits on stress and mental health, can protect lung function and can enhance vaccine effects (Sallis & Pratt, 2020). Unintended negative outcomes such as a reduction in physical activity and an increase in sedentary behaviours were hypothesised due to lockdowns (leading to closures of gyms, the cancellation of exercise clubs and a reduction in incidental exercise) and quarantining (Chen et al., 2020). Lower physical activity and increased sedentary behaviours (TV watching) were found to be associated with poor mental health indicators (self-reported feelings of loneliness, sadness, and anxiety; Werneck et al., 2021).

1.7 Mental health

Mental health in the context of the pandemic is an important factor to consider, not just because of the significant impact poor mental health can have but because of the relationship between poor mental health and susceptibility to physical illness. Research has shown that having a diagnosed mental health condition/problem increases people's risks of catching a cold by 44% (Adams et al., 2013). Although no single explanation for this link has been found, several have been suggested including behavioural factors such as reduced help seeking in people with a diagnosis of depression, reduced cell-immunity and increased inflammatory processes in those experiencing depression and stress (Coughlin, 2013). To understand the psychological impact of the current pandemic therefore can be important from a public health perspective.

In addition, Taylor et al., (2020) found COVID related stress was more prevalent (38% of the sample) than numbers of people who had contracted COVID-19 or known someone who had (2% and 6% respectively) suggesting the psychological impact of COVID-19 may be greater than the medical impact. The psychological impact of COVID-19 varies across country in terms of severity and prevalence, but some similar patterns have been found globally (e.g. increase in anxiety, distress, depression and stress) and so literature from countries across the world will be included below (Sameer et al., 2020). Although the use of western constructs of mental health and their applicability worldwide is rightly called into question (Mills & Fernando, 2014), their inclusion here is to provide an accurate reflection of the current literature. Issues of constructing distress as a 'disorder', the often-ignored issues of context (culture, poverty, social inequality), the validity of mental health constructs, the assumption that western constructs of 'mental health' will fit other cultures, and the impact of exporting these ideas as a colonialization of 'knowledge' and a loss of cultural diversity (Mills & Fernando, 2014) should be held in mind throughout as an underlying issue with the research into this area.

1.8 Prevalence

Prevalence studies globally have found variable rates of stress, psychological distress, depression, sleep disturbance, anxiety, and PTSD. Rates for anxiety symptoms have ranged from 6.3% up to 50%, for depression rates vary from 14.6% to 48.3%, psychological distress and stress from 8.1% to 81.9%, PTSD symptoms from 7% to 53.8% and sleep disturbance from 18.2% to 50.5% (Forte et al., 2020; Huang & Zhao, 2020; Robillard et al., 2020; Smith et al., 2020; Sun et al., 2020; Wang et al., 2021; Xiong et al., 2020). Most studies on this topic are cross-sectional in design and did not have any prior prevalence rates for the participants tested so the direct impact of COVID-19 could not be assessed. However, studies which did use previous data to assess the impact of COVID-19 or asked participants to rate symptoms prior to and during the pandemic showed a worsening of these symptoms and/or an increase in diagnoses (Robillard et al., 2020; Sun et al., 2020).

Explanations given for the varying prevalence rates globally included government response to the pandemic and the timing of data collection (at the height of infections, during lockdown measures, at the start or during the pandemic; Forte et al., 2020; Lin et al., 2020). Even in countries with successful COVID-19 containment and limited restrictions such as South Korea (schools, places of worship and other public spaces were closed), findings have shown clinically significant levels of depression and anxiety, an increase when compared to other studies looking at prevalence rates of mental health difficulties prior to COVID-19 in the country (Lee et al., 2021). Government responses have also been suggested to have an impact on the long-term prognosis of mental health symptoms with a longitudinal survey measuring mental health symptoms (stress, anxiety, PTSD and depression) finding that the prevalence and severity of these did not increase over time despite an increase in the confirmed number of COVID-19 cases (Wang et al., 2020). The authors theorise the rapid response of the government, as well as preventing further spread of COVID-19 may have acted as a protective factor for mental health.

In the few studies which did not find any changes in mental health, the government's prompt response to the pandemic including its dissemination of information, it's financial support of employers and self-employed people and the country's pre-existing social welfare and healthcare system were thought to be protective factors (Van der Velden et al., 2020). Those who had physical health problems were more likely to experience high levels of anxiety and depression and low levels of emotional support, but this was also true of that group in the years preceding the pandemic (Van der Velden et al., 2020). Other explanations for lack of change include high socio-economic status of some participants meaning that respondents had better health outcomes and were more likely to have job security (Jarego et al., 2021).

1.9 Causes

Within the literature, various causal pathways have been suggested and evidenced to explain the link between mental health and the pandemic including quarantining which has been shown to cause stress, anxiety, exhaustion, and higher rates of PTSD, depression and insomnia (Brooks et al., 2020). Stressors during the quarantining period included the duration of the quarantine, fear of infection, boredom, inadequate supplies of basic necessities (i.e. food), and lack of information from public health authorities. Financial loss and stigma from others post-quarantine were found to be additional stressors. Wierenga et al (2021) found that anxiety and depression were linked to emotional responses and concern about COVID and that those with depression reported COVID as having an increased impact on their lives. Additionally, participants who felt they had more control over being infected experienced less anxiety than those who reported less perceived control. Personal social distancing behaviour and stay-at-home orders have also been shown to have a negative impact on mental health (Marroquin et al., 2020) possibly due to a reduction in social contact which has been found to lead to impairment in mental health (Benke et al., 2020). Others have argued that it is fear of infection rather than social distancing or lack of human connection that causes subsequent mental health difficulties as fear of infection drives adherence to social distancing (Silva et al., 2021). Similarly, Boyraz et al., (2020) found that it was perceived vulnerability to COVID-19 which increased COVID-related worries and led to heightened perceived social isolation and traumatic stress.

1.10 Jobs

Other factors found to influence mental health include job security, with insecurity associated with self-reported ratings of anxiety and depression (Aguiar-Quintana et al., 2021). Bierman et al., (2021) found that exposure to financial hardship during the pandemic had a significant effect on psychological distress even when controlling for levels of financial hardship pre-pandemic suggesting that job security or the presence of adequate support packages from the government are key in mitigating mental health issues.

For those working during the pandemic, for example hospitality staff, psychological distress and substance misuse were higher in U.S. restaurant workers who were still working during the pandemic compared to those who had been furloughed suggesting the additional stress of working during the pandemic and increased risk of infection were key factors (Bufquin et al., 2021). Additionally, the U.S. government offered benefits to those workers who had been furloughed or sacked which may have mitigated the impact of job uncertainty/financial difficulty and therefore well-being in this group suggesting the importance of government support packages for people during this time. For other staff who returned to work during the pandemic, no increases in psychiatric symptoms have been found potentially due to the use of preventative measures by employees and organisational preventative measures (workplace hygiene and concern for employee health) (Tan et al., 2020).

A major change in work during the pandemic has been the move for many office workers to working from home. Wang et al., (2021) examined the effect of remote working during the pandemic in China and found that workers reported issues with work-life balance, effective communication, procrastination, and loneliness. Participants reported that certain work characteristics, such as how much job autonomy they had, impacted on their experiences with those able to decide how and when to work benefitting from improved well-being and performance. Participants whose workplaces provided online spaces for them to connect reported less loneliness.

1.11 Relationships

Relationships have also been affected by the pandemic. Philpot et al., (2021) conducted a longitudinal study assessing participants' emotional support, friendships, loneliness, perceived rejection and hostility pre-Covid (in February 2018) and compared this to during the pandemic. They found that participants reported increases in emotional and instrumental (practical) support during the pandemic, fitting with their hypothesis that individuals use social support to manage stress and that this strategy was less organically available during a period of relative isolation. Similar findings were found by Park et al (2020) who showed that participants actively seek emotional support from others to help manage during the pandemic. Participants also reported higher levels of loneliness and decreased feelings of friendship. However, the measure used to assess friendships included items about how often people meet friends, something which has been prohibited due to social distancing measures, potentially affecting the construct validity of this measure.

The restrictions imposed by the pandemic have affected people in all familial circumstances. Couples living together have faced increased stress due to being confined in close quarters. Those with small children, or those with older children at home for longer periods of time due to school closures have also been negatively affected (Eleuteri & Terzitta, 2021). Furthermore, social distancing guidelines and lockdowns, have led to couples living apart finding it harder to connect while single people wishing to engage in casual sex have found reduced opportunities to engage in this activity (Eleuteri & Terzitta, 2021).

It is clear from the research presented here that the pandemic has had a significant impact on the general population but an issue with quantitative studies looking at populations is that marginalised groups, who are often a numerical minority, and their experiences can be missed or underreported. Marginalised groups are often already at a higher risk of mental health difficulties, social isolation, and job insecurity (Wilkinson & Marmot, 2003) so studies on general populations, even when including demographic information on these groups, may not be enough to capture the complexity and nuance of the experiences of these groups. As discussed earlier, some marginalised groups are at greater risk of severe illness and death from COVID-19, with one theorised reason being the increase in prevalence of chronic illnesses in these groups. How then, given the potential increase in risk from COVID-19, has this group membership influenced their experiences of the pandemic?

1.12 Why Chronic Illness?

People with chronic illnesses are more likely to be unemployed, experience social stigma and isolation and have co-morbid psychiatric diagnoses or experience mental health challenges (de Souza et al., 2018; Pettinicchio et al., in press; Vogel et al., 2020;). This group are also more likely to experience health disparities even before the pandemic (Pleasants et al., 2016). An additional key factor with this group, however, is the impact of the rapid reorganisation/cessation of health care services, as those with chronic illnesses more frequently access healthcare (including outpatient appointments, follow-ups, and treatments) than those without chronic illness (Consonni et al., 2020). The impact of redirecting services to help manage the pandemic, the cancellation of outpatient appointments and 'elective' surgeries and the financial cost of the pandemic potentially leading to years of austerity and further cuts to healthcare services, is likely to have significant consequences for disease management and prognosis (Manderson & Wahlberg, 2020).

Studies have also indicated an avoidance in accessing healthcare services due to the pandemic. Lazzerini et al., (2020) reported that in Italy, hospitals saw a drop in emergency department visits from 88% to 73% with the Paediatric Hospital Network reporting 12 cases in a single week of delayed access to hospital care which resulted in severe illness and, in several cases, death. When interviewed, parents had failed to bring their children to hospital earlier due to fear of COVID-19 or because hospital visits had been discouraged to reduce risk of infection. Accident and emergency visits have also declined in England by up to half in some areas causing concerns that people are avoiding accessing treatment and that this will eventually lead to a larger impact on health services later due to complications (Thornton, 2020).

Lim et al., (2020) raised issues regarding the secondary impact of COVID-19 on those with chronic illness predicting an increase in worsening chronic illness cases. As people in this category are deemed higher risk from severe or fatal complications from COVID-19 they have been encouraged to stay home and avoid routine follow-ups. Although some can be conducted via telephone, the priority for most healthcare trusts is the management of COVID-19 with many routine appointments being deferred indefinitely. With the increase in immobility due to remaining home and the potential psychological impacts of the pandemic on this group, their health may deteriorate over this time meaning that, post-pandemic, there may be an increase in demand of health services due to complications or deteriorations for people with chronic illness.

The WHO noted the additional burden to those with chronic illnesses in their press release (WHO, 2020) where they gave specific advice for those with underlying conditions on how to manage the pandemic and look after their mental health. Additionally, in the context of increased isolation and social distancing, loneliness has been shown to impair people's ability to self-manage their chronic illness and impact on people's perceived ability to manage their illness (Liu et al., 2020). Those with chronic illness were identified as particularly at risk for serious complications from COVID-19 infections and so many were told to self-isolate or shield cutting them off from social supports, medical care and making accessing basic necessities difficult (Manderson & Wahlberg, 2020). The assumption that people would be able to self-manage their illnesses in the context of isolating, whilst balancing the risk of attending clinics against the potential for infection from COVID, along with monitoring fluctuations in their condition and being able to access doctors and pharmacists and get prescriptions as necessary needs to be investigated further as little information or guidance exists for these groups (Manderson & Wahlberg, 2020).

Furthermore, “physical exercise is medicine” (Pedersen & Saltin, 2015) for several diseases including neurological, metabolic, pulmonary, cardiovascular, and psychiatric conditions so evidence suggesting that people are reducing their physical activity and becoming more sedentary may be even more problematic for those with chronic illnesses. Additionally, studies reported above on the increased levels of stress and distress found in the general population, may also uniquely impact those with chronic illness. The impact of stress on disease and self-management has been highlighted in models such as that by Cohen et al., (2016) and their Stage Model of Stress and Disease. Their paper highlights the predictive role stress plays in both disease progression and morbidity and argue that environmental events (such as bereavement) can lead to stress appraisals (threatening or not) which in turn alter the functioning of the hypothalamic-pituitary-adrenal systems, heart rate and blood pressure. In studies comparing the general population to those with chronic diseases, people with chronic diseases reported higher levels of depression and anxiety (Gorrochategi et al., 2020). O’Neil et al., (2020) discussed the implications of COVID-19 and the containment attempt (isolation, social distancing, quarantines) and their impact on the psychosocial and mental health of those with cardiovascular diseases. Mental health issues have been shown to have a significant effect on cardiovascular disease with those experiencing even moderate distress more at risk of death or complications meaning that mental health and its predictors (psychosocial etc) need to be monitored and treated throughout to prevent a future healthcare crisis.

To summarise, the existing literature on the general population has identified key areas of impact for people during the pandemic. These have included physical and mental health, work, and relationships. For those with chronic illness, their experiences of these areas prior to the pandemic were already at odds with the general population with rates of unemployment, isolation, mental health, health care usage and health disparities being higher in this group (see above). Although studies of the general population include those with chronic illness, they are a numerical minority and so their experiences are lost. It is important to capture these experiences as research suggests they will likely be different to those without chronic illness.

1.13 Scoping Review

To understand what is known about the experiences of the pandemic in those with chronic illness

, a scoping review of the current literature was conducted. It is important to note that while chronic illness is the term used within the literature, in NHS services long term conditions are used to describe this population. For the purposes of this thesis, chronic illness will be used to adhere to convention in the literature. Whilst papers looking at the general population include reference to those with chronic illness (usually included in demographic information), the papers included below are those that focus solely on this population as the main focus of study.

1.13.1 What is Chronic Illness/Disease

It is important to clarify what is meant by the term 'chronic illness' or 'chronic disease'. For the purposes of this thesis, chronic illness/disease is defined as any illness that persists for a long period of time, requiring continuous support, care and treatment at least periodically to manage symptoms, and has no cure (Dubouloz, Paterson, King, & Ashe, 2010).

1.13.2 Search Strategy

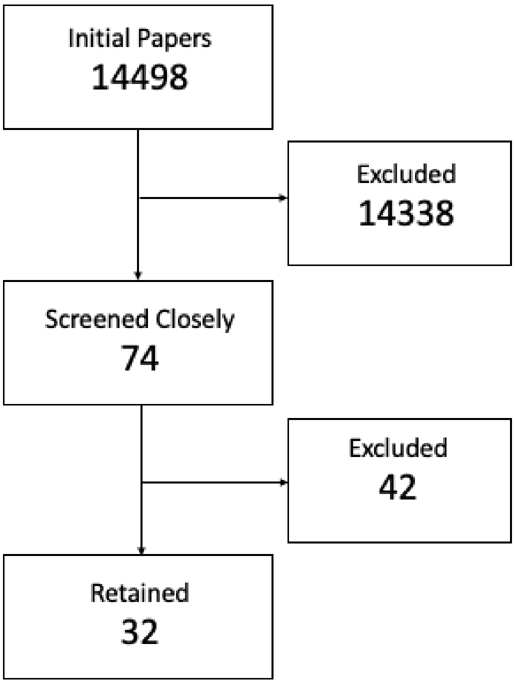
A variety of databases were searched (PsychInfo, Science Direct and WHO's COVID research database) in order to identify published literature on the experience of the COVID-19 pandemic for people with chronic illness. Search terms used included "chronic illness or chronic disease", "long term conditions", "adult", "COVID-19, coronavirus or 2019-ncov or sars-19" and "experience/attitudes/feelings".

1.13.3 Overview of Results

14, 498 papers were found using the search terms across all databases of which 14,338 were excluded (these included opinion pieces, commentaries, editor letters, theoretical papers which did not include any data, papers in foreign languages, papers discussing the treatment of and vulnerability to COVID-19, papers focussing on specific sub-groups such as healthcare workers, and duplicates). This left 74 papers which were reviewed more closely. On further inspection, an additional 42 papers were deleted for the reasons highlighted above, leaving 32 papers to be fully reviewed. All the articles were written in English and published between 2020 and 2021 and no methodological approach was excluded. During the closer review, a further 10 papers were reviewed and discarded keeping the total number of papers at 32 (see Figure 1).

Figure 1

Scoping Review Search Results



Of all the papers collected, only one used a qualitative research design (Hyland & Jim, 2020), the majority being cross-sectional and quantitative. The papers either considered chronic illness in general, collecting information from participants with a variety of illnesses or focussed on a specific illness from the outset. Illnesses which have been specifically investigated include epilepsy (Assenza et al., 2020; Hees et al., 2020; Koh et al., 2021; Mueller, et al., 2021; Vancini et al., 2020), lung cancer (Hyland & Jim, 2020), chronic obstructive pulmonary disease (COPD; Gonzalez et al., 2020), irritable bowel syndrome (IBS; Sabate et al, 2020), multiple sclerosis (Kalron et al., 2021; Ramezani et al., 2021; Vogel et al., 2020), hypertension (Browne et al, 2020), cardiac issues (Farooqi et al., 2021; O'Neil et al., 2020), cystic fibrosis (Radtke et al., 2020), diabetes (Bala et al., 2021; Fisher et al., 2020), chronic pain (Consonni et al., 2021), Parkinson's (Xia et al., 2020) and chronic fatigue syndrome (CFS; Moncorps et al., 2021). Broadly speaking, topics of the research include mental health, physical activity, adherence to illness management plans, access to healthcare, health and in particular COVID literacy, and coping. One paper also developed a measure of COVID-19 'fear' specifically for those with chronic illness (Wu et al., 2020). Appendix A provides a summary table of the empirical papers found in the literature search including which countries the studies were conducted in.

1.13.4 Critique of 'self-management' in people with illness

Before the literature is reviewed in detail, an important critique should be highlighted as it is a theme which underscores much of the research included below. That is the concept of 'self-management', the idea that those with chronic illness should manage and take ownership of their health, following guidance on treatment and preventative strategies

(Fletcher et al., 2019). The idea of self-management leads to the implication that the cause of chronic disease and therefore it's successful management, lies within the individual's lifestyle choices and is not related social determinants such as racism, social and economic disparity, lack of food, or gendered violence which research has shown to be some of the biggest factors influencing chronic disease (Galvez et al., 2020). By ignoring the social determinants of health, populations most disadvantaged are more affected by illness and poor health outcomes than the general population (Williams et al., 2021). Although demographic factors are often measured in the studies below and used as factors to identify better or worse outcomes, no real discussion or consideration of the complexities of these social determinants and how they play a role in the outcomes measured is given which is a significant limitation of all the research presented below.

1.13.6 Mental Health

Studies investigating the psychological impact of COVID-19 on those with chronic illness have included studies on specific groups like epilepsy, multiple sclerosis, irritable bowel syndrome, and studies across groups under the umbrella term of 'chronic illness'. They have used a variety of measures to assess mental health, including the Impact of Event Scale-Revised, the Patient Health Questionnaire (PHQ-9), Hospital Anxiety and Depression Scale (HADS), or the use of specific questions designed by the researchers for example 'have you experienced any changes in anxiety within the last 14 days' (Pettinicchio et al., in press). Prevalence of mental health difficulties varied between studies with 27.6% to 50.4% reporting anxiety (Hees et al., 2020; Ramezani et al., 2021; Pettinicchio et al., 2020; Koh et al., 2021), 18.8% to 51.9% for depression (Hees et al., 2020; Ramezani et al., 2021; Koh et al., 2021; Irmak et al., 2020) and 38.9% reporting an increase in stress (Pettinicchio et al., 2020). Studies which compared those with chronic illness to those without, found participants with chronic illness (IBS and Parkinson's) reported significantly higher levels of anxiety, depression, sleep problems and fatigue compared to those with no illness (Sabateet al., 2021; Yu et al., 2020).

1.13.7 Causes and risk factors

Polenick et al., (2021) looked at factors predicting/related to sleep disturbances in people with chronic illness and found that worry about infection, financial issues and loneliness were associated with more sleep disturbance. Participants reported that fear of themselves or loved ones being infected was a primary concern followed by lockdown and a loss of social contact, boredom, loss of routine and isolation (Sabate et al., 2021). Pettinicchio et al., (2020) found that experiencing financial difficulty and concern regarding catching COVID-19 significantly predicted anxiety and stress levels with social isolation predicting stress levels only. Fear of COVID-19 was also higher for those experiencing mental health symptoms compared to those without (Ramezani et al., 2021). Addis et al (2021) found that those aged 35 and older, females, those who had a longer duration of chronic illness, those who had respiratory symptoms in the past two weeks and those with no social support were significantly more likely to experience a negative psychological impact.

Wu et al., (2020) developed a measure of COVID-19 fear specifically for those with chronic illness. Initial items were developed by asking those with chronic illness (specifically scleroderma) to list 1 to 10 fears in relation to the COVID pandemic. One hundred and twenty-one people took part and their answers were coded into common themes and items were developed. These included fear of becoming infected, leaving the house or collecting supplies and being unable to access basic supplies, not being able to access health care, that they would be isolated for longer due to their condition, they will be infected and experience severe complications, not receive adequate care, and health professionals will not be familiar with the needs of their condition, people close to them will become infected, and they will not be able to access medication for illness due to shortages. The study found good internal consistency reliability and convergent validity and that all items reflected a single dimension.

The only qualitative study in this review, looked at the experience of COVID-19 for patients with lung cancer. Hyland and Jim (2020) found that participants experienced heightened levels of perceived risk of contracting COVID-19 due to their cancer, that all participants had changed their behaviour due to the pandemic, often going beyond government guidelines due to feeling more vulnerable, and that they experienced a range of emotions including scared, frustrated, anxious and depressed with single participants reporting feeling lonely. They shared methods of coping which included social support and patients discussed the loss of things COVID had taken from them such as meaningful activities and a loss of independence.

1.13.8 Health Literacy

Health literacy is defined as the ability to understand health-related terms and facts and using this knowledge to promote health related behaviour to improve or prevent illness (Gautam et al., 2021). When applying this concept to COVID-19, Addis et al., (2021) found that, in a sample of patients with chronic diseases (hypertension, diabetes, heart disease and multiple illness), 30% had ‘poor’ knowledge about COVID-19 (as rated using Bloom’s cut-off point). Predictors of ‘good’ knowledge of COVID-19 included living in urban areas, younger age and being better educated. 81% had a ‘good’ attitude towards COVID-19, assessed by asking questions regarding their view on safety measures (i.e. ‘it is important to keep my distance’, ‘washing hands is essential’ but also on positive views of the government’s ability to control the pandemic). Of the participants questioned, 34.6% had ‘poor’ prevention practise meaning they were not engaging in recommended guidance such as avoiding unnecessary travel, frequent hand washing, wearing masks and so on.

Gautam et al., (2021) looked at the role of health literacy in patients with chronic illness. They noted the dual impact of the pandemic for those with chronic illness; the need to prevent infection of COVID-19 due to increased vulnerability and the need to maintain current health due to reduced health-care availability. The European Health Literacy Survey was conducted on an Indian population along with awareness and adherence to COVID-19 safety measures and adherence to recommended self-management strategies for their illness (medicine and physical activity). The researchers discovered almost half of participants found it hard to understand health-related information regarding preventative measures and health promotion behaviours. Whilst all were aware of COVID-19, 81.2% were unaware of asymptomatic presentations and one-third did not know about vulnerable sub-groups (those more at risk from the disease). 41.7% did not know what healthcare was available currently or during lockdowns and nearly a third reported poor adherence to social distancing, mask wearing and coughing etiquette. One third had stopped taking medicine and almost half had reduced or stopped routine physical activity. Health literacy significantly predicted adherence to taking medicine, COVID-19 awareness and engaging in preventative behaviour.

1.13.9 Physical Health

Da Silva et al., (2020) looked at physical activity levels during the pandemic for people with chronic illness and whether sociodemographic factors influenced this relationship. Of the 249 participants interviewed, 71.5% were not meeting recommended physical activity levels and 62.7% were sitting for more than 4 hours per day. Being a woman and a smoker significantly predicted not meeting recommended physical activity levels. Similar findings were reported by Saqib et al., (2020), Kalron et al., (2021) Cransac et al., (2021) and Browne et al., (2020) with physical activity decreasing in 45% to 50.8% of the participants and Browne et al. (2020) reporting an increase in sedentary behaviours in participants with hypertension, which can lead to cardiovascular diseases and events. Despite these figures, the remaining participants either reported no change or an increase in exercise during this time.

Smoking was found to have increased in 30.3% of cardiac patients (Chague et al., 2020) and in 25% of patients with chronic coronary syndromes (Cransac et al., 2021) potentially having an impact on disease destablisation. Reasons given for the increase in smoking included stress and inactivity (Chague et al., 2020).

For physical health in terms of symptoms of chronic illness, Koh et al., (2021) found that 13% of epileptic patients reported a worsening in their epileptic symptoms (either frequency, duration, or severity) and participants perceived the reason behind it being related to stress, insomnia, and physical tiredness. Issues with access to medicine were also reported which may have caused an impact with 11.5% adjusting their dose to prevent running out and 24.3% reporting difficulty in getting medicine. Seizure worsening and psychological stress all predicted poorer quality of life. Similarly, Assenza et al., (2020) found 18% of epileptic patients sampled reported worsening of their seizures. Bala et al., (2021) looked at self-care practises in patients with diabetes and found that the majority continued to engage in physical activity and good diet self-care, however blood-glucose testing and foot care was low with 85.19% and 83.33% respectively reportedly not checking. Fisher et al., (2020) noted that increases were reported by participants of diabetes related stress and social isolation compared to pre-pandemic and half reported struggling to manage their diabetes (reportedly eating more and exercising less) since the pandemic began with a quarter of participants reporting high glucose blood levels since the pandemic started.

For some groups of people with chronic illness, lockdowns have proved beneficial; in one study COPD patients reported a reduction in exacerbations and an improvement in their symptoms possibly due to reduced infection of other viruses or bacteria and a reduction in pollution (Gonzalez et al., 2021). Radtke et al., (2020) looked at the effects of the pandemic with people with cystic fibrosis and found that most of the participants were still engaging in daily maintenance therapy (clearing air ways, inhalation therapy and physical activity). Those who were not engaging as normal in their therapies reported that a lack of supervised training, lack of motivation and lack of structure to their days were the cause.

1.13.10 Healthcare Access

Schwartz et al., (in press) looked at the pandemic's impact on services for people with chronic health conditions and disability and found that most, regardless of financial, educational or social privilege experienced a loss in healthcare services.

As part of Fisher et al's (2020) study, they also investigated how the pandemic had influenced participants' access to care and ability to obtain medical supplies. Forty percent had had their appointments cancelled with others reporting a switch to telehealth appointments. Those who experienced telehealth appointments 45% were less satisfied compared to face-to-face appointments. A third of participants reported concerns in being able to obtain food but only 9-15% reported worries around accessing needed diabetes supplies.

Mueller et al., (2021) looked at health care during the pandemic for patients with epilepsy (PWE) in particular prescription data in order to assess adherence to medication. For longstanding PWE, the study demonstrated an increase in prescriptions prior to the national lockdown in Germany however their data suggests that newly diagnosed PWE were undertreated during the lockdown due to a significant decrease in prescriptions for this group. Referrals to hospitals for further investigations also decreased over the lockdown period but it was not possible to identify a cause for this reduction (whether due to lack of services, hesitancy in doctors or in PWE).

Hees et al., (2020) also researching epilepsy patients, found difficulties accessing appropriate medication were reported by 19.6% of the sample due to medication being unavailable, no longer having the finances to pay for it due to pandemic related job loss and restrictions on travel. Twenty-two percent of the sample reported financial problems including difficulty paying for food and bills. Similarly, Pettinicchio et al., (in press) found almost half of their sample reported the pandemic had impacted their finances and in Vogel et als.', (2020) study 37% reported changes in working with some reporting a reduction in working hours and job loss. Other patient groups also reported difficulty in accessing medicine. Vogel et al., (2020) found that MS patients reported difficulty and delay in accessing medicine, 10% had made changes themselves to their dose and dosing schedule, a quarter of whom did so without input from their neurologist.

1.13.11 Appointments

Chudasama et al., (2020) investigated impacts of routine care on people with chronic illnesses by questioning healthcare professionals. Only 14% of professionals reported they continued their face-to-face appointments with the majority either reducing these or using telephone or online appointments instead. Sixty-seven professionals reported moderate to severe effects on their patients due to changes in health care provision with 80% of professionals reporting their patients had worsened mental health. Saqib et al., (2020) looked at the impact of COVID related lockdowns in people with chronic diseases using an online semi-structured questionnaire. Forty-five percent of participants noted an impact on their health with more than half missing routine check-ups, and reporting issues with availability of medicine.

When face-to-face appointments were available Vogel et al. (2020), in their study of MS patients, found that 64% cancelled appointments due to concerns regarding COVID. Sabate et al., (2021) found that out of 23.6% of participants who had modified medical experiences, 37.2% had cancelled appointments due to fear of going to the doctors.

Assenza et al., (2020) looked at the impact of the pandemic on epileptic patients and found for 95% of their sample, outpatient appointments were postponed, PWE had worse depressive and anxiety related symptoms than those without epilepsy and 18% reported worsening of their seizures.

1.13.12 Coping

Umucu and Lee (2020) looked at the impact of COVID on stress and coping in individuals with disability and chronic disease. They found that coping strategies accounted for 54% of the variance in people's well-being with denial, use of emotional support, humour, religion and self-blame all associated with better well-being (after controlling for demographic factors). Across the sample, moderate levels of stress, depression and anxiety were recorded and the most common coping strategies implemented were acceptance and distraction. The types of chronic illness and disability participants had was not recorded.

Consonni et al., (2021) looked at the impact of those experiencing chronic pain due to two different underlying diseases comparing them to healthy family members (control group) to ascertain what further impact COVID-19 may have had on this group. Those with health conditions rated their quality of life and physical health lower compared to the control group and also reported higher use of “dysfunctional” coping strategies (viewed here as catastrophism, helplessness, rumination and magnification). Half of the participants reported moderate to extreme changes in their daily living including work, household management and out-of-home habits but what these were specifically and in what ways they had changed were not recorded.

Moncorps et al., (2021) looked at people with chronic fatigue syndrome (CFS; a medically unexplained condition) and their coping strategies during the pandemic, comparing them to others with recognised diagnosed diseases. They found that CFS patients used less social support and problem focused coping strategies than others with recognised illnesses.

1.14 Critique of literature

The current literature demonstrates that those with chronic illness have been similarly affected by the COVID-19 pandemic as those in the general population, experiencing mental and physical health issues. In the few studies that compared the two, people with chronic illnesses appear to have worse mental health difficulties and report worse physical health and quality of life than the general population. People with chronic illness have also been impacted by healthcare issues and medication shortages; however, it is unknown whether similar experiences of these exist for the wider population. Many of the studies include multiple diagnoses under the umbrella term of chronic illness and several chronic illness types have no studies at all looking at their experiences of the pandemic. Given the variation in aetiology, bodily systems affected, prognosis and treatment across different chronic illnesses, these oversights may mean significant differences in experiences are lost. This becomes problematic when attempting to address the needs of these groups at policy level as some needs may go unmet due to lack of knowledge.

Although there is a burgeoning literature on COVID-19 and its impact on those with chronic illness, the literature is largely questionnaire based/online studies using a cross-sectional design. While the information obtained is useful, it lacks a more detailed understanding of the experiences of those with chronic illnesses and the use of pre-written questions may prevent people participating from sharing the things they feel most important, and instead reflect the interests of the researchers. This may explain why there is a focus within this literature on adherence to health behaviours and healthcare access (something which is considered important by healthcare professionals) and no studies were reported focussing only on employment or relationships as seen in the literature on the general population. Given this is the largest pandemic experienced in the Western world in living memory, to assume you can capture people's experiences without first conducting more qualitative work to uncover what people would choose to talk about seems limited. Additionally, the studies described above span the globe with studies taking place in Africa, India, China, the U.K and U.S. The ability to generalise findings from other countries to U.K. populations may be limited given the variation in cultures, healthcare systems and pandemic responses.

1.15 Congenital Heart Disease (CHD)

CHD is an umbrella term for a range of birth defects affecting the heart (NHS, 2021). The severity of CHD and its impact on those with the diagnosis varies depending on the type of defect present, with some babies requiring immediate surgery and others not needing surgery until later in life (if at all). It is one of the most common forms of birth defect affecting approximately 1 in 100 babies born in the U.K. Whilst some defects improve on their own over time or require no further intervention, for many, treatment is needed throughout their life including surgeries, medication, and regular monitoring to check for deterioration (NHS, 2021). CHD populations are at greater risk of developing respiratory tract infections and endocarditis (because of other infections spreading to the heart).

CHD is one of the chronic illnesses that has not received any attention in the literature so far. Of the 7 papers that do exist on the topic of CHD and COVID-19, four were theoretically driven arguments for the management of services during the pandemic and the potential risk of those with CHD from COVID-19. The remaining papers discussed paediatric CHD (El-Saiedi et al., 2020; Malviya et al., 2020). No studies have been conducted looking at the physical health, relationships, mental health, employment or healthcare access for this group.

Although there is limited data on how patients with CHD respond to COVID-19, Gilca et al., (2010) found that those with CHD were more likely to be hospitalised, need ICU treatment and had greater risk of death from influenza than the general population and a study conducted by Yu et al., (2006) after the SARS pandemic found that the disease caused significant cardiovascular complications. Those with CHD are offered vaccinations against influenza due to their increased risk of death (Bare et al., 2018) so research suggests that CHD population may be at increased risk from COVID-19 than the general population. It is thought that COVID-19 causes damage to the heart via three routes: indirectly due to an overwhelming immune response, directly through infecting cardiac muscle or by hypoxia due to respiratory damage (Tan & Aboulhosn, 2020).

Due to the variability of presentations in adults with CHD (ACHD), the usefulness of U.K. government guidelines for this group is poor (Gatzoulis et al., 2020) leaving it unclear where guidance for this population will come from. The importance of maintaining a healthy and active lifestyle in this patient population as a means of managing symptoms and improving prognosis has also been highlighted (Farmakis et al., 2021) meaning that any impact on these factors for this group could be significant. Due to advancements in treatment, survival rates for CHD have increased meaning that adults with CHD are a growing population in terms of size, with an increase in this population of 57% in a 10-year period in some parts of the world (Marelli et al., 2014). In the UK, ACHD has a prevalence rate of more than 4 per 1000 adults and the number of these patients with complex disease is increasing (NHS England, 2016).

Given the variability of the disease, its presence from birth, the complications of an ageing population meaning more people have ACHD and with more complex presentations for the first time, the ability to extrapolate data on other chronic illnesses to this group are limited. It was therefore decided that this group would be the focus of the research question, using a qualitative design as there is currently no information on this group in relation to their experiences of COVID-19. Based on the previous literature, the following research questions were developed;

- How have people with CHD being impacted by the COVID pandemic?
- Has the pandemic influenced their mental health and physical health during this time?
- What has made it easier or harder for people with CHD during the pandemic?
- What do people with CHD want from their NHS services in terms of adaptations and support?

2. METHOD

2.1 Overview

In this chapter the epistemological and ontological positioning of the research will be discussed as well as the method used to address the research question. The design, ethics and research procedure used will be outlined along with participant details, and the approach to data analysis.

2.2 Ontological and Epistemological Positioning

Before beginning the process of research, it is important to consider the epistemological and ontological position of the research, as it provides a framework within which data is collected, analysed, and understood. First, to understand these concepts, ontology is a branch of philosophy that considers the nature of reality; what exists and what it is to be Tracey, 2013). Epistemology is a branch of philosophy concerned with knowledge; what knowledge is, how we acquire it and to what extent and on what basis we can claim to know something (Willig, 2012).

In social sciences, the two ontological positions that have been particularly influential are those of realism and social constructivism/relativism. Realism argues that there is a single truth or reality which exists independently of us and is possible to know through scientific research and theory. Healthcare research and practise (which follows an evidence-based approach) is traditionally rooted in realism where for example physical complaints (such as pain or cancerous growths) are measured 'objectively' either through mathematical measurements (e.g., size or speed of growth) or via questionnaires thought to accurately capture real world phenomena (Gannon, 2020). Social constructivism/relativism, however, argues that there are multiple realities and that people's experiences of the world are shaped through a person's culture, history, and language (Wiliig, 2012). Language therefore is central to the constructivist approach as it shapes an individual's reality. Constructivists argue that people's experiences and descriptions of a phenomenon are equally valid, and that no interpretation of the phenomenon is more right or wrong than the other.

As the research questions for this thesis make the assumption that people's group membership (i.e., having a diagnosis of CHD) would alter the way in which people understand and think about their experience of what is considered a 'real' event (i.e. the covid-19 pandemic), the study outlined here falls into the philosophical position of critical realism. It is argued that there is an intransitive world (that is real; the pandemic) which exists outside of ourselves but that our experience of this world is shaped by our perceptions and theories of it (transitive; Houston, 2010). Therefore, the researcher acknowledges the existence of a 'truth' and is therefore ontologically realist, but recognises we are unable to know that truth fully because our experience of it is shaped by our culture and context, therefore epistemologically relativist (Bhaskar, 2008). To apply this argument using critical realism's three levels of reality, the covid-19 pandemic is real (at the actual level) which is affecting people's lives, but how this pandemic is experienced (the empirical level) will differ between individuals based on several contextual factors and social structures (real or causal level; Houston, 2010). What this research is interested in, is the effect (i.e. observable events) that the pandemic and it's interplay with people's contexts has had. From a critical realist position, it is recognised that this attempt to acquire knowledge of people's experiences of the COVID pandemic cannot be objective due to the contexts of both the participant and researcher and that the 'truth' of this experience can never be fully known.

2.3 Methodology

As the research questions posed for this thesis were aimed at understanding how people's contexts influenced their experiences of the COVID pandemic, an area of research which is novel but rapidly expanding, a qualitative methodology was chosen, applying a participant-led, inductive reasoning approach. Quantitative approaches were discounted as the aim of the research was not to test a theory or demonstrate causality and there is no current theory that suggests what to measure and how to do it. Qualitative research is inherently interpretative, as data given by participants is analysed through a specific lens which itself is shaped by the aim of the research, the epistemological positioning of it and the type of analysis used (Willig, 2012). Although a descriptive analysis would capture more succinctly the voice of the participants, this approach is better suited to a direct realist position. As the epistemological position of this research has already been outlined as critical realist, it is not assumed that a person's account of their experience is the same as their 'actual' experience and so some interpretation about the meaning behind a person's account and how it has been influenced by their context, is indicated.

Although there is little research on critical realist informed methodology (Fletcher, 2017) there are several approaches to data analysis that are compatible with this position including Grounded Theory (GT; Oliver, 2012), Discourse Analysis (DA; Tracey, 2013), and Thematic Analysis (TA; Braun & Clarke, 2006). Interpretative Phenomenological Analysis (IPA) is grounded in phenomenological epistemology and was therefore not deemed appropriate in this instance (Braun & Clarke, 2006). Although GT can be applied in a critical realist frame, its main purpose is to develop theory from data which is not one of the aims of the current study. Rather than develop a theory, the study aims to identify some of the challenges faced by those with CHD in relation to the pandemic and what factors have made their experience easier. Additionally, the aim of the research did not include a focus on understanding the discursive construction of people's experiences or on the language people use so DA was also discounted as an approach.

TA was chosen as the method of analysis for the study as it compatible with a range of epistemological standpoints, including critical realism (Braun & Clarke, 2006). TA allows the researcher to examine people's experiences across a data set, reporting patterns, and generating (at times unanticipated) insights into those experiences demonstrating a distinction between an 'actual' experience and a person's account of that experience. Although the approach allows for inductive reasoning, the view that themes 'emerge' from the data ignores the role of the researcher in actively constructing the themes, and the influence on the research of their own professional knowledge, experiences, and beliefs (Taylor & Ussher, 2001). Thus, although the approach allows for themes that are strongly linked to the data, it is not purely inductive.

2.4 Design

Semi-structured interviews were chosen to collect data (see appendix B for interview schedule) as this method is compatible with TA and they are easier to arrange than focus groups where multiple participants have to be available at the same time. The semi-structured nature allows space for the participant to talk about what is important to them while also allowing the researcher to keep the focus on the research question and aims (Willig, 2012).

2.5 Participants

Ethical approval was granted by the University of East London (UEL) School of Psychology Research Ethics Committee (see appendix C and D for the application and approval). Additional approval was sought at a later date to request permission for recruitment to be conducted via a charity and with an amendment requested by that charity to add their details to the debrief form (appendix E for amendment approval). Further approval was given by The Somerville Foundation's Research Council, a charity for people with CHD who aided in the recruitment of participants by advertising the research on their social media platforms.

2.5.1 Sampling and Recruitment

Prospective participants were recruited through The Somerville Foundation's social media accounts (Twitter and Facebook) using an advert developed by the researcher (appendix F). Inclusion criteria for the study were that participants were aged between 18 and 65 years (and therefore of working age), have a diagnosis of CHD, must speak English sufficiently well to participate in the study, must have access to a computer and the internet to join the virtual interview, and must currently reside in the U.K. and have lived in the U.K during the COVID pandemic. People who expressed an interest in participating in the study were sent an information sheet (appendix G) and consent form (appendix H) to sign and return to the researcher before interviews took place. A follow up e-mail was sent after 1 week if no response was received but this was the only additional communication sent to prospective participants. Eleven people contacted the researcher for further information on the study and a total of nine participants took part in the actual interviews. One potential participant was unable to take part due to poor health and the second did not reply after expressing an initial interest.

2.5.2 Participant Demographics

Nine participants completed the interview and were included in the data set. Below is a table of their demographics. As the table shows, seven women and two men participated in the research with all but one participant identifying as White British. Further demographic information has been removed to protect participants identities.

Table 1

Participants' demographic information

Name (pseudonym)	Age	Gender identity	Ethnicity
Rebecca	44	Female	White British
Danielle	47	Female	White British
Hannah	43	Female	British Indian
Sarah	32	Female	White British
Michael	49	Male	White British
Adam	40	Male	White British
Zoe	54	Female	White British
Isobel	35	Female	White British
Leah	Unknown	Female	White British

2.6 Research Procedure

2.6.1 Data Collection (Interviews)

Once participants had returned their consent forms (signed electronically), an interview was scheduled through e-mail to take place using Microsoft Teams software. Due to the COVID-19 pandemic, it was not possible to offer face to face interviews in this study. Semi-structured interviews were completed with interviews ranging from 70 to 120 minutes in length. The interview schedule was used flexibly, allowing participants to guide the conversation as they wished so the format of each interview varied depending on the participants' experiences. At the start of each interview, an additional verbal explanation of the research, aims, procedure, data storage and handling was given, and verbal consent requested. Participants were given opportunities to ask questions and the opportunity to request to be audio recorded only by turning off their cameras before the recording commenced.

Given the nature of the interview, a discussion about a pandemic in which participants were at a higher risk of serious illness and death, measures were taken to reduce and manage any distress participants might experience. Participants were made aware of the topic in advance and were informed that they had the right to stop the interview at any time or to refuse to answer any question they did not wish to. The structure of the interview was considered, with questions posed in the initial stages of the interview designed to give participants time to feel more comfortable with the researcher (questions on the history/type of CHD they had, how they first heard about the pandemic and when they realised that the pandemic was going to have a major impact in the U.K.). The researcher also used the clinical skills acquired during her training to notice signs of distress and provide the participant with a safe space in which to discuss their experiences.

At the end of the interviews, participants were given an opportunity to discuss any issues they felt important that had not been covered and to reflect on the interview and their experience of it. A debrief was e-mailed to all participants directly after the interview (appendix I) with contact details for charities which could provide additional support to participants if they wished. All participants were given contact details of the researchers involved in the study and were given the opportunity to decline further contact (planned follow up e-mails with a summary of the findings) if they wished, although none took this offer. The findings of the study will also be disseminated via The Somerville Foundation through their mailing lists, website, and social media.

All names used in interviews were changed using pseudonyms to protect the identity of the participants involved. Recordings were stored on UEL's OneDrive in a password protected folder and only the researcher and supervisor had access to the recordings and transcripts. All recordings were deleted upon completion of the transcript and all transcripts will be destroyed two years after the study's completion.

2.6.2 Data Analysis

2.6.3.1 Transcription: Interviews were transcribed verbatim using Microsoft Teams software which was then checked thoroughly by the researcher with identifiable information such as names of people or places removed. As TA does not require the same level of detail as discourse or conversation analysis, an orthographic transcript was developed with special attention paid to the use of punctuation to ensure that in the writing of spoken word, the meaning was not changed (Braun & Clarke, 2006). Each transcript was read multiple times to familiarise the researcher with the material, a key part of data analysis when using this methodology (Bird, 2005) and initial ideas written about what parts of the transcript may be of interest in relation to the research aims. Notes made in a reflective journal following the interviews were also consulted to add context to the material.

2.6.3.2 Generating Initial Codes: Codes are "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p.63). An initial list of codes was created by annotating the transcripts and highlighting parts of the work that held particular interest to the research question to help identify patterns in the data (Braun & Clarke, 2006; see appendix J). These codes and the extracts they related to were later put into an excel spreadsheet, with a second sheet listing the final codes and initial ideas for themes (see appendix K).

2.6.3.3 Searching for Themes: Once a comprehensive list of codes had been collected, they were organised into potential themes with similar codes being grouped together to form an overarching theme. Codes were written onto separate pieces of paper and grouped together physically to help visualise the different themes and sub-themes that might be found within the data (Braun & Clarke, 2006; see appendix L).

2.6.3.4 Reviewing Themes: The themes created were reviewed using Patton's (1990) criteria of internal homogeneity and external heterogeneity to ensure that the codes within themes were similar and that each theme was distinct from the others. The themes were also compared to the original data set to ensure that they adequately reflected the data.

2.6.3.5 Defining Themes: Once the thematic map was finalised (see appendix M), attempts were made to describe and name the themes to capture their defining feature and why the theme was of interest in the context of the research questions. The final summary of themes is presented in the following chapter.

2.7 Reflexivity

Given the role of the researcher in qualitative research in interpreting and therefore transforming the data and the power that comes with the ability to control what aspects of someone's experiences are shared, reflexivity is an important facet of good practise. It is therefore important to orient the reader to the personal and professional experiences of the researcher so that the research itself can be fully contextualised (Braun & Clarke, 2013).

I am a final year clinical psychologist trainee who has never worked in health psychology or with people who have chronic health problems such as CHD before. I do however have my own lived experience of the COVID pandemic which motivated in part, the topic of the research as it interests me personally. I do not have any experience of what it is like to live with a chronic illness but made the decision to shield during the pandemic to protect vulnerable family members. It should be noted however that in between data collection and transcription/analysis my husband was diagnosed with cancer and my family had to shield for the duration of his treatment. This experience may have shaped how I approached the analysis with codes that matched my own experience being given undue attention. It may have also made me more sensitive to some of the underlying unspoken themes that arose during the interviews such as the cognitive and emotional burden participants faced due to having to manage their own health, wellbeing, and safety. I also felt more keenly the frustration and fear participants spoke of at the lack of response from the government and from others who did not follow COVID safety measures. I am a White British middle-class woman from a relatively poor working-class family, and so I am mindful of how people's privilege may have shaped their experiences of the pandemic (for example being asked to shield in a spacious house with a garden, compared to being asked to shield in a small, crowded flat with no access to a private outdoor space). My political leaning is very much in discord with that of the current government and I disagree at a fundamental level with their policies, world view and handling of the current pandemic.

Throughout the interviews, I tried to be mindful of how my own context and beliefs may shape my approach to questions and responses to participants who may have different contexts and beliefs from me. I tried to ensure I maintained a neutral and curious stance throughout the interviews; however, my position (as a White British woman, a NHS worker, mental health worker, a professional) will have remained present throughout. I kept a reflective journal throughout the research process to think about how I may have influenced the research process (see appendix N for an extract).

3. RESULTS

3.1 Overview

In this chapter, the research findings, developed following the methodology outlined in the previous chapter, will be presented. First the data will be situated followed by introducing the three themes and nine subthemes constructed from the data. Following this, each theme and its subthemes will be discussed in more detail using excerpts from the transcripts to support their validity.

3.2 Situating the data

Participants in the sample had varied contexts with some living alone, others living with partners and two living with multiple family members (including parents, siblings, partners, and children). Within the sample, all had been informed of their increased vulnerability to Covid-19 and five participants had been instructed to shield during the pandemic. In the sample, only one person had experienced a Covid-19 infection.

3.3 Themes and Subthemes

Three themes and nine subthemes were constructed from analysis of the data as summarised in the table below.

Table 2

Themes and subthemes

Theme	Subtheme
Vulnerability	Differing relationships to a new label
	A new way of life
	Uncertainty and risk
	Others and 'othered'
	Trust
Wellbeing	Wellbeing difficulties
	Coping and resiliency
Connections	Staying connected
	Loss and strain

3.4 Theme 1: Vulnerability

The first theme identified was that of vulnerability. This theme refers to the label given to people with underlying health conditions in relation to their potentially worse outcomes of Covid infection (ie. severe illness and death).

3.6.1 Differing relationships to a new label

For all participants, there was already an awareness that they may be more susceptible to severe illness and death from Covid compared to others. However, some highlighted that this was the first time they had ever felt vulnerable due to their heart condition.

> REBECCA: It was the first time that I sort of felt vulnerable as a result of my heart condition in terms of…… yeah, in, in terms of sort of how it might impact my life, my continual existence.... the idea that it made me vulnerable to this kind of big and scary disease that was that was hard to take in

The label of 'vulnerable' from the British Congenital Cardiac Association (BCCA) led to a variety of responses from participants many of which were negative. Some highlighted the sweeping generalisations made by these labels which didn't acknowledge the variation that could be found in terms of health within a given diagnosis. For others the psychological impact was clear as some participants had worked hard to build up their confidence in terms of what they were capable of, many had never viewed themselves in this way before and others highlighted that the label of 'vulnerable' lead to feelings of vulnerability.

> ADAM: I mean I think I was just put out by the terms that they used. You know I think it comes back to that 'vulnerable' term and I'm not, I've spent I'd say 10-15 years getting rid of lack of confidence due to thinking that you know you can't go and do something or erm and getting into a position where I've gone from that to being OK to being quite you know quite, quite on the upper end of capability if you like from a mindset point of view at least or a physical capability.... I don't think anybody should be in a position where they actually feel vulnerable

> LEAH: I've never had to think about myself like that before, especially being a burden or something, it's kind of weird

For some there was a clear tension between the utility of these labels in terms of the protection and access to services they gave and the cost that came with the label and being identified as different. The quote below summarised this tension nicely.

> LEAH: I wouldn't want to go out into the world or whatever and be like 'oh she's got a something wrong with her' kind of thing like I don't, I don't tend to think like I said

> before like I’ve got anything wrong with me per se? So I don’t like being put in this ‘other’ category. So I wouldn’t want to highlight that. But then equally when I’m out and about obviously you can’t tell that, but I’m anxious because I don’t want people to come near me or whatever... but I don’t really see a way out of that because no one really wants to be that other person who’s, whatever. Seen as less or whatever… but then equally you want to be safe for yourself so it’s kind of a.. it’s a funny one (laugh)

Further nuance around participants relationships to these new labels was highlighted by some for whom being told they needed to shield meant risking their job and financial security.

> ZOE: So he got a phone call from the shielding helpline and um, so got this phone call from the shielding helpline saying register if you need help. So he said well I don't need help, he says I'm not actually in the category... and that was actually quite important to Dave because he, as I said he works, does contract work and the company that he was working for had um, got rid of, but, but when people that short term contracts you can pay people off with two weeks’ notice so they had actually got rid of, got rid of the few people that were high risk because they just simply, they said they couldn't make the workplace safe for them that… they didn't want them there.

Others also found a lack of shielding status valuable as it reduced their feelings of threat and was viewed as a positive.

> HANNAH: 'cause I didn't get the shielding letter, you know, I think, I think if I got the shielding letter I probably would have freaked out a lot more

Challenges around these labels were further compounded by mixed messages from professionals around who was most at risk from Covid with some heart teams deviating from the advice given by the British Congenital Heart Association. Others continued to explain that even within teams there appeared to be some incongruence with teams advising shielding and yet booking appointments in around people’s work.

> ZOE: You know, so they’re, so they're saying on the one hand you know [specific diagnosis] people should be shielding. And the other hand the, they’re timing things around about his work commitments you know. So just the, the message, is just… completely off

3.4.2 Subtheme 2: A new way of life

All participants described changing behaviours in some way to avoid or reduce the likelihood of infection, many conducting their own risk assessments regarding the safety of their activities and work. Some looked to others to help guide their risk assessments with most seeking guidance from medical professionals, social media or proactively looking up government guidance on how to keep safe. Some had a keen awareness of Covid rates across the UK but also in their own area and used this information to judge the risk of travel and attending events/activities. All these factors highlight the cognitive load involved for this group in terms of accessing information and making these risk decisions.

> ZOE: we did go out a few times, but it was thinking about this sort of, was there too many people you know, was it, did it feel safe?

All participants also spoke of following government guidance in the use of PPE, social distancing and increasing hand hygiene. Most participants went further than the guidance for example cleaning groceries before they entered their homes and one family even developed routines for others living with them on entering the house from work/school as they were unable to shield properly due to living with others and shielding guidance not being practical.

> ISOBEL: 'Cause the government's guidelines were really just unworkable for most people, you know, I have to stay in my room all the time. We've only got one bathroom in this house so I couldn’t have had my own bathroom... The way I managed, you know, around the shielding thing and like say, both boys have sort of, as soon as they got home cleaned, got cleaned up and stuff

Further planning and thought were given by participants making the decision to lockdown or shield before being told to and others preparing for the possible changes due to the pandemic before anything was announced by the government.

> ZOE: we didn't do any of the panic buying or anything because I thought this is coming so I started to lay down some stores a few weeks before so we weren’t in there arguing over toilet rolls or anything like that

People reported workplaces and companies putting in place safety procedures for jobs unable to be done from home and the satisfaction this gave for those who needed to continue to work in person. Others described having to negotiate their own safety protocols with places such as schools to ensure they could maintain a sense of safety again emphasising the additional burden that fell on participants to manage during this time. For those participants whose employment meant they were unable to work from home (WFH), they spoke of the privilege needed to be able to WFH or stop working during this time, particularly in terms of the financial security needed. This an important factor given that people with chronic illnesses are often less financially stable and in lower paid jobs, often ones which were unlikely to be moved to WFH.

> ZOE: if [our consultant] had said actually you are extremely clinically vulnerable, you should be shielding... we would have been in a situation where we simply, we would have been saying to ourselves well is £115 a week, you know, having to weigh up the risks of Dave going out to work and us having no income or very little income

The emotional burden and anxiety that came with these decisions was highlighted in a quote by Danielle.

> DANIELLE: George started working September, and part of me wanted to kill him like really wanted to kill him, 'cause I'm thinking why are you going to work, you know how vulnerable I am... it's been sitting on me for months I really, I'm not comfortable with him going to work

All participants spoke of avoiding certain activities and places to manage the risk of catching Covid-19. Many of the sacrifices made by participants, were of activities that were important to them highlighting further the emotional cost of the changes made. Many in the sample cancelled their medical appointments due to the risk of infection even though some had a need for them due to health concerns. For these participants, they were left in a position of having to hope they would be okay.

> LEAH: the last one was like ‘oh we need to do a test to check oxygen levels which are kind of important right not, because your oxygen levels are lower than they should be when you did your exercise test’ and I was like ‘oh’ and ‘we need to work out why that is so we need to book you in to get that checked’ and it’s like ‘okay but now’s not a good time because if I catch Covid then my oxygen levels go’ (laugh)..... yeah you just have to sit and wait and see what happens really don’t you, just hope nothing happens (laugh) in the interim

Others cancelled appointments or avoided contacting medical professionals due to an awareness of services being strained. All participants experienced telephone or virtual appointments during the pandemic with many highlighting the positives of these interactions such as punctual appointments and lack of extensive commutes to attend specialist centres. Some participants highlighted the need for the NHS to continue to utilise technology to stay in contact with patients and offer services but the importance of flexibility was highlighted as moving to online technology may result in the exclusion of some without adequate means. All participants expressed disappointment at not hearing from their heart teams during the pandemic and a desire for more contact from them but what this should look like was up for debate. Due to a lack of contact, several participants found themselves needing to contact friends or family to get medical advice.

> HANNAH: my sister's a doctor and she trained with erm, someone else who I've known since I was 15 and she'd actually joined the same team as my cardiologist. And because I had a personal number I actually just messaged her about it

All participants reported utilising outdoor spaces to meet with others and exercise while maintaining distance. This increased use of outdoor spaces meant that for parts of the year the weather impacted on their ability to maintain their new way of life with adverse weather leading some to take further risks by meeting indoors or stopping going out altogether. This variation in safety behaviour was also seen over time with participants beginning to relax their initial safety behaviours as the pandemic continued.

> MICHAEL: During the first lockdown I didn't go out other than to exercise. Didn't go to shops, didn't go even just to a local shop across the road and you know nothing and didn't do any of that... I've relaxed a bit on that, um so now I'm going to some shops, went to the hardware store today

Many described an acceptance of the way their life had changed or a general feeling of people 'getting on with things' which led to changes in what they spoke about with friends and is potentially related to this relaxing of safety precautions as Covid-19 became more 'normal'.

> HANNAH: Whereas now, sort of, 'cause everyone's kind of in the same boat like third lock down and working and living… I guess what we talk about now is a lot more sort of general about, you know what we're doing or what we're watching and things like that, rather than how we're feeling.

Some participants expressed openly a desire to no longer have a CHD diagnosis where before it had not played a large part in their lives, mainly due to being unable to live their life due to the increased vulnerability this diagnosis gave regarding Covid.

> LEAH: I've always thought 'you know I'm quite healthy except for that little thing that, you know, who knows what's really happening with it' so I think that was like 'ooo okay so basically that does mean for me at least life is gonna completely stop' and obviously we didn't really know what was gonna happen more widely in the country anyway. Erm, so yeah, so I think that was that first 'oh okay I wish I didn't have anything wrong with me now'

3.4.3 Subtheme 3: Uncertainty and Risk

Uncertainty was a key issue that appeared to increase feelings of threat/lack of safety. There were several sources of uncertainty identified by participants, with a key issue being the severity of covid should they get infected, a fear which was compounded by an uncertainty over who was infected.

> LEAH: I mean I would definitely say fear would come out because, you know, thinking “oh God, if I go and catch this does that mean I’m just gonna end up dead?’ because there’s not treatment for this or anything

Further uncertainty arose for participants who all reported actively seeking research and evidence on Covid and its potential impact on those with CHD. The lack of scientific evidence and knowledge on this failed to reduce uncertainty leading to some being over-cautious to try and maintain a sense of safety. Further uncertainty appeared to focus on how effective their safety measures were at reducing the risk of infection and serious illness. Questions were raised about the effectiveness of PPE

> SARAH: I started wearing a mask months before anybody else did because I just couldn't see that how that wasn't the right thing to do. You know, I mean, whether it prevents it completely is a different matter but even if it gave you a 10%, 20% reduction in transmission, I mean, it's inconvenient, and it's not very pleasant, but so be it.

This uncertainty around covid severity, who was infected, and the effectiveness of PPE impacted people’s perceptions of risk. For some, a lack of shielding status put them at greater perceived risk due to a lack of protection within the government guidelines for those who fell outside of that category but were still deemed highly vulnerable. For some, workplaces did not factor in their vulnerability without supporting evidence in the form of a shielding letter.

> MICHAEL: they were saying, well, you know, because of the current guidance, we can't give you a shielding letter so um, but we would classify you as highly vulnerable... When lockdown one ended, I was then immediately asked to start visiting young people... they said unless you’ve got a shielding letter, we can't do anything about it you need to visit.

Even for those shielding however, living with others, increased their risk

> SARAH: So she's been in and out, and she's quite often does two or three trips a day. Umm and it may be out for an hour at a time, so I think... she's a risk in sense if she could bring something back, and that bothers me, but that's not, you know, I mean, I know it's, early on she was very concerned about me.

The impact of this uncertainty and subsequent perceived risk led to feelings of fear and discomfort for most participants when social distancing wasn’t maintained and for one participant being made to work in an unsafe environment led to difficulties in mental health and the loss of their job causing financial concerns.

> MICHAEL: the demographic in [place name] which showed the highest number of Covid cases was the demographic I was working with, so immediately it was kind of right, we need to be careful here.... I was being asked to do this position and to be honest I did do it for a few weeks and then it just caused me so much stress and so much anxiety, I mean, I was going into young people who were having multiple connections with multiple people who had Covid, and were telling me that. And although I was wearing masks and stuff like this I was still vulnerable, I was putting myself at risk and it caused me a massive amount of stress and in the end I had to basically go off sick and I didn't return to that job.

For some, the risk of getting long-haul covid and new covid variants increase in anxiety which then caused participants to change their behaviour more.

> LEAH: I think as soon as this new variant started it was like ‘ohhh’ that kind of made me more anxious about going outside so. I have stayed in a lot more

Many participants had personal experiences with Covid through the illness and/or death of someone they knew or more distally through contact with others with a CHD diagnosis. These experiences often highlighted the risk of infection, leading to an increase in fear or anxiety, especially when they involved the participant directly and lead to a ‘near-miss’ Covid infection.

> MICHAEL: [he] had actually been showing symptoms in a cough and stuff two days later, he was taken into hospital, um three days after that, he died... at that point, for me, um, it was fear central

It is important to note however, that for some these experiences brought a feeling of safety as stories of others surviving Covid were shared by professionals and others via social media.

> ZOE: I think he phoned round about 500 of his patients, of his CHD patients and just to see how they were all getting on. So he was actually very reassuring in that although some of their patients had um contracted this Covid that they had actually done very well.

Following on from participants relaxing their safety precautions as time went on, many spoke of their discomfort and anxiety at being outside again after shielding or being in lockdown for so long. These feelings were mostly related to being at greater risk outside and not being able to control their environment, but one participant highlighted additional difficulties around knowing how to behave and what the rules were, having been at home for so long.

> ISOBEL: 'cause Phil kept saying “will you nip to the shop?” you know when I've been and I'm like “well when I go down what do I do?” He says “what do you mean?” I was like “well, do I queue outside like I've seen on the telly?” and he's like “no they're not doing that anymore. You just walk in, but if there’s someone like stood sanitizing their hands you have to give them you know the space. I was like “OK then”, but before I went to Sainsbury’s, Morrisons sorry, I was really like apprehensive like is there a one-way system? Is there's so many allowed in at the shop? Will this, this and this happen? You know is the sanitizing around the shop or is it just at the beginning? And he was like “just follow me you'll be fine” and you know, and he had to sort of reassure me all the way around.

Further interactions between uncertainty and risk were highlighted in the extract below where being outside caused uncertainty due to not knowing what constituted as ‘safe’. The risk was increased in these situations due to the invisible nature of participants’ CHD meaning others were not taking precautions around them.

> LEAH: the first few times it did make me quite nervous because it was just kind of this uncertainty like ‘are they too close? Is someone wearing a mask?’ and because I, if you met me on the street you’d think I’m fine right?... so you can see quite easily cos I live in an area where there are quite a lot of older people, like its quite suburby and everyone’s usually quite cautious about going around the old people for example but for me it’s just like they walk right past me unless I move obviously. So it’s, you know, yeah because they are seen as like they are physically vulnerable

Further causes of uncertainty arose from the potential indirect effects of the pandemic on people’s health and the inability to know if health had deteriorated due to lack of scans and reviews by professionals. All participants in the sample had appointments cancelled or delayed during the pandemic.

> ZOE: the complexities of CHD, you know, sometimes there’s subtle things that, that might indicate that there's something going on. You know you, you don't always pick up on that, or you, you compensate and don't always, you know, sort of realize that you're compensating. Ah, sitting down to chop the vegetables instead of standing up to chop the vegetables you know. So you make these little compensations... and I, I'm

> sort of worried that people aren't getting scanned and things and aren’t then getting, those things aren't getting picked up on

This also highlighted the inappropriateness at times of online or telephone appointments where these scans and checks could not take place. In addition to these concerns, participants highlighted how non-specialist services struggled to understand their condition and so some participants avoided standard hospitals and A&E services as they were uncertain, they would receive adequate care. Further uncertainty for this group also arose during the pandemic due to changes in services meaning participants were left not knowing how to access needed medical services.

> DANIELLE: When it came round to the test, the surgery caught covid so it closed for two months so I was like OK, now I don't know what to do

3.4.4 Subtheme 4: Others and ‘othered’

All participants spoke about the opinions and behaviours of others and the importance of collective responsibility to keep everyone safe given that vaccinations have not been approved for children and many with underlying health conditions, especially CHD fall into this younger age category. All participants spoke of others not following government guidelines to reduce the spread of Covid and the impact this had on them. The lack of rule following by others was reported by some to be the direct cause of them avoiding busy places, going out at unusual times or in fact going out at all as discussed above.

> MICHAEL: there is a baseline current of anxiety, I think really um of... yeah, how do I keep myself safe when all around me aren't, it appears, there's a lot of people who are, but there's a lot of people who are just not.... it makes me cross and angry that people just aren't being careful and not taking good care, because the impact is ultimately very poorly people or dead people

Some also spoke of the difficulty they had in asking people to follow the rules or move away from them when they got too close and for others, children especially were difficult to manage due their lack of awareness and understanding of the need to keep socially distanced. How to manage these relationships was spoken about particularly by one participant who ultimately reduced contact with children in their family to keep safe.

> DANIELLE: So she, she came over and she gave me the biggest hug and I kind of froze, which was awful... I hugged her but for the 10 days after I was absolutely terrified that I’d caught something

Many reported feeling anger and frustration at others’ lack of rule following, viewing them as ‘bonkers’ or ‘stupid’ especially when discussing the popularity of anti-vax views and conspiracy theories around Covid. Most of the participants interviewed spoke of the differing experiences they had had, compared to others without underlying health conditions and how their vulnerability status and the need to adapt to stay safe, had resulted in their lives being stopped while others continued living.

> REBECCA: my friend... we're the same age and we've known each other for years and, um she has different health conditions but none, none that make her more susceptible to, to Covid and she has been to work more, um, she's been on the train although she doesn't drive so she doesn't really have a choice about that but she's been on the train, she’s been on the bus, she's been to exercise classes and Pilates classes, you know, inside and I haven't done a lot of those things, and she's been to the shops you know, quite, just more often, and I know that I've done less because of my kind of concern about.. not getting ill.

For many this led to feelings of frustration and a sense of injustice that their lives would continue to be limited, particularly when others were not following Covid guidelines. For some with specific diagnoses, there was a general concern that the longer the pandemic took, the less time they would have ‘healthy’ to live their life and achieve their goals before their health deteriorated.

> ADAM: no matter how fit you are you have a window of opportunity or a window of quietness if you like and it is not a circulation that will very likely sustain a normal lifetime so it will at some point fail and your route is transplant or death and which sounds morbid but I don’t mean it to be it’s just you know something that you get to know and process and you know it’s better to process it and deal with it. And I kind of thought if this goes on for five more years or something this might ruin my window of opportunity

Participants also spoke of the role of the government and their response to the pandemic, which was viewed negatively by all participants. For many, the lack of prompt response, initial discussions of herd immunity and the perceived poorness of the rules and government actions compounded their fear as they felt that Covid was not being taken seriously and that they were being viewed as expendable.

> SARAH: They blanketed a lot of people in, in one group and just assumed that herd immunity would happen and the world would go on and, and you know that, and also... they seemed to think it was acceptable to think that way. Okay, you sacrifice how-, however many thousands for the greater good and that, that is acceptable. And also the more I've seen it, also it's people think that, you know it's, it's almost as if they say, well, one life is worth more than the other... And that, that, on what level is that acceptable?

> ZOE: so very much my frustration was around about, you know, the, the, the, the government's lack of, lack of doing anything you know that, that was really, um, was really… infuriating becau-, when you could see it coming.... even at the hospital I just thought ‘oh you know, they're just not taking this seriously’ although they had banned visitors the, the sort of basic hygiene in the ward and I had to, to make a comment about, uh, nurse that was just going from patient to patient doing injections and stuff and not washing their hands or sanitizing her hands in between and, and it was just like I can't believe this, is just basic hygiene, you know, basic, basic infection control. I was just like you know, this is coming and nobody's taking it seriously

Other issues arose for the sample regarding other’s opinions and views about those who fell into the ‘vulnerable’ category. Every participant in the sample spoke of hearing others (whether that be people they knew, individuals on social media, politicians, or government policies more generally) consider them as burdensome, problematic or their lives as expendable.

> ISOBEL: She was like, “well, you need to think outside the box, if you just stayed indoors without, you know, everyone else is vulnerable, we don't. You know the economy, the economy is on its arse and it's because we're protecting people like you”, that's what she said. And I was like “I'm not a species”, I was like “you wouldn’t say that about, like, a black person, so why are you saying it about someone who's, you know, vulnerable? It’s kind of discrimination”.

> REBECCA: it makes me think they've got their priorities wrong. Because they are seeing the opening of the system, which is obviously incredibly important as more important than, I suppose people's lives… My life

These messages of ‘less than’ or ‘problem’ narratives led some participants to justify their own value by devaluing others with underlying conditions as less worthy, highlighting the roles they play in society, in particular their employment status, and pointing out that children and young people can also fall into these categories. These justifications reflected wider society’s views on who is valued.

> MICHAEL: I mean it's the same old argument that I have con-, continually I was born with this, it wasn't my fault or a lifestyle choice... However, someone who eats themselves to diabetes can get a shielding letter. It is baffling, you know, 'cause that's a lifestyle choice do you know, and so for me it became aggravated, the concept of not being able to be protected.

> SARAH: a lot of people with underlying health conditions, and they can be, you know, they can be kids, they can be teenagers... you've had a transplant, whether you've had cancer treatment, whether you've got Lupus, whether you've got M.E, you know, there is so much.

3.4.6 Subtheme 5: Trust

All participants in the sample spoke of actively looking for research and data on Covid as well as its impact on those with underlying health conditions. Many used science to explicitly guide their choice of safety precautions such as mask wearing using the evidence to support their decisions. This appeared to reflect an implicit trust in science as reporting or reflecting the ‘truth’. By extension, this trust was also applied to medical professionals and governing bodies who had expertise in this science.

> ZOE: you know trust the science and trust that… what the experts and British Congenital Cardiac Council had decided was actually the thing to stick to... So it was just trying to hang on to the science and not get swept up in the, in the sort of um, emotions of it

For one participant, a lack of trust in mainstream media and it’s reporting of the pandemic motivated his search for original research to obtain information and others expressed a more general mistrust and disappointment in the media for failing to hold the government to account for its actions.

> ZOE: the kind of other things that drives me mad and it is the lack of um.... what would you, what do you say, like the um... like the media's lack of, um, questioning of the government, you know th-, they've not challenged the government, nobody has challenged the government

All participants expressed disapproval over the government’s actions during the pandemic with several explicitly highlighting their lack of trust in the government and its motivations.

> ISOBEL: so like some people say I’ve been over the top, some people think I'm, you know, “it's ridiculous why you doing this? The government have not said you've got to do that”, and I'm like “because I don't trust any”, you know have to, it's like I don't trust anyone anymore. You know, they say it, how do I know that they’re telling the truth sort of thing?

Another important factor in terms of trust and feelings of safety appeared to be the quality of relationships between participants and their medical teams. In this sense participant’s CHD provided a unique experience of medical professionals as many participants had known their consultants for a significant length of time and this provided them with a more intimate knowledge of one another. When speaking of his consultant one participant said:

> ADAM: your relative who understands completely your heart and what you've been through and that, and all the, any questions or concerns you might have had and was you know, coming away from that phone call I just thought 'yeah, just feels better'.... I don't really have a, a relationship with my GP.

Some participants raised concerns around how their personal medical information was being used during the pandemic, with information seemingly being shared between organisations without their permission. This include apparent data sharing between GPs, government, local councils and even supermarkets who were provided lists of those considered high risk.

> ZOE: we got a knock on [the door] one Saturday morning. And it was this person from the Council saying that, um, you're, you're on a list and you haven't registered for any services and Dave's saying well, I'm not on the list he says I don't know why you've got my, you know name and all of that, so I was really, I was really quite upset about this because I felt as if it was a real invasion of our privacy

An additional issue of trust was raised around the ability of patients with underlying conditions to trust that they would be offered the best care and that medical decisions would be made in their best interest following announcements around the NHS rationing treatment to those with better potential outcomes.

> ADAM: If the NHS is completely overrun then we're going to have to start making hard decisions about who gets treatment and who doesn't and then that will be based on you know who we consider will be more likely or less likely to have a good outcome and for me, I kind of think "well I would come into that potentially less likely outcome".... if you're not in healthcare with that approach of everyone matters then you shouldn't be there, and I think it's almost perverse when they talk about it like that.

Further erosion of trust toward NHS services could be seen in participants reporting failures in adequate categorising of some patients, people being missed off vaccination group lists due to miscommunications and lack of follow up care. This resulted in participants having to routinely chase care and be aware of the care they ought to be receiving adding further to the cognitive burden this group faced as discussed above. One participant spoke of her difficulty around accessing vaccinations as her GP and cardiology team continued to bounce her back and forth when trying to get added to the correct grouping for vaccine priority. The time and effort the participant had to put in to get her CHD recognised was significant

> HANNAH: It's just been frustrating, I guess if I've been working right now, I'd just be like screaming. I mean, I guess 'cause I've got the time, I've been able to do it.

There were additional stories from participants of not receiving shielding letters for several weeks and some not at all until they raised the issue with medical staff at their appointments. One participant had to get creative to get access to the advice she was supposed to have due to her shielding status.

> DANIELLE: in the nicest possible way she's like ‘you shouldn't be going out’, I was like but I said ‘I've not had a shielding letter’ I said ‘I am shielding but I've not had a letter’...my auntie in [place name] is shielding, and so she kind of read her letter to me until I had mine like okay, yeah, that makes sense, that makes sense

Participants also reported a general lack of understanding of the needs of their group from local councils meaning inappropriate care was offered.

> LEAH: then the council as soon as I got the letter randomly called me and I was in the middle of these big long walks and he was like ‘oh do you need someone to, to come and help you get dressed and get washed’ and I was like I’m in the middle of some woods right now I think I’m good (laugh) and that was so late in the day that that, that came through

3.5 Theme 2: Wellbeing

3.5.1 Wellbeing Difficulties

Many participants described wellbeing issues during the pandemic. For some these issues were new, but for others previous mental health issues returned or were exacerbated by the pandemic. The participants who spoke most about difficulties with their wellbeing tended to be those who lived alone although everyone mentioned some form of worry, fear, anxiety, or stress. These issues fluctuated with participants reporting periods of difficulty followed by periods of relative ease. Many experienced overwhelming emotions at particular points throughout the pandemic for example when a new lockdown was announced or when considering their increased risk of mortality. For one participant, the deterioration in her wellbeing caused fear in itself:

> REBECCA: I was getting like, feeling properly down and actually it was quite scary because I've never experienced that before

Deteriorations in wellbeing had a knock-on effect for some participants physical health as during times of difficulty, exercise regimes were reduced leading to a decline in physical health. Additionally, the stress of the pandemic lead directly to heart related issues and a motivation to maintain wellbeing to stay well:

> LEAH: at times it did make me have more palpitations which isn’t fun, so that’s kind of been more like ‘God okay I’ve got to manage this stress and not have that’ cos you know… I have been very thinking consciously right okay, you’ve gotta do this just for your own health and just stay well?

Participants identified several causes of mental health difficulties some of which were highlighted in the previous theme of ‘safety’ as for some, a lack of perceived safety was a primary cause. Other causes not yet discussed included the impact of the duration of the pandemic and the loss of hope that accompanied this.

> REBECCA: It was the… new year you always feel optimistic about new year, you know 2021's going to be better than 2020.... And all of that, suddenly like that feeling of a certain level of optimism, it just felt like it had all been taken away. It was all gone and it was just looking grim and grim and grim

For some, the pandemic meant they were unable to utilise their usual coping strategies to manage through periods of difficulty as they usually relied on contact with others for support. People also spoke about the tiring nature of keeping up with the rules and safety guidance on top of the media reporting of death tolls and repeated reports of fatalities amongst those who had chronic illnesses.

> SARAH: do we really need a daily death toll? I don't think we do. Um, you know, because it becomes oh... so, you know, so tiring, you know, you're trying to keep up with what do you do? What can't you do, what you know an etc but then you also get oh well actually we've had 500 deaths today

Social media also had a negative impact on wellbeing with several participants reporting they had deleted or reduced their use and others reporting that not just news but others’ opinions had made social media seem depressing. Being exposed to others’ anxieties also had a negative impact on participants own wellbeing and lead to some participants reducing contact with friends and/or family members to try and manage this.

> LEAH: I did start to feel bad after a bit of time because I was constantly getting that nervous energy, or anxious energy from other people like ‘woah, you should be like really careful’ and ‘oh are you okay?’

For some participants, having to stay at home all the time was difficult especially when their temperament situated a busier lifestyle and the choice of remaining at home was not theirs.

All participants spoke of finding the pandemic harder to manage in the winter months due to the bad weather and early darkness preventing walks outside after work.

> DANIELLE: It got to me you know, I would say from October till probably Christmas time I was the world's worst because I couldn’t go out in the garden, couldn't really go for walks 'cause the temperature got too cold, haven't seen my mates for a really long time

For many the winter months compounded feelings of loneliness and isolation, especially for those who lived alone although others who lived with family members also spoke of loneliness when partners went to work or children out to school.

> REBECCA: what didn't help was that I was on my own at, I told you that I live on my own and I, because of all this, you know social distancing I ended up being on my own for a very long time, I think it was eight or nine weeks where I didn't have a conversation with a person

Of the three participants who reported using support bubbles (implemented by the government to allow those shielding to mix with others), all of whom lived alone, two found these incredibly helpful (with the third having to limit her use of the support bubble due to the increased risk of her support network attending work/school). The significant difference between these bubbles and visiting with friends and family outside was the opportunity to interact normally with someone.

> REBECCA: the support bubble thing. Um, I can't remember when they brought them in but that, it's a huge, makes a huge difference. I mean, because, I know obviously my parents are a way away so they you know they can't be around here all the time, but, and I can't be around there, but having, being able to have someone who you can interact normally with… is really, really important

Many participants spoke of losing a sense of purpose during the pandemic either through loss of work/volunteering positions and the difficulty of filling their time whilst at home. Several reasons were suggested for this including having more time to ruminate on their situation, losing a sense of self-worth and achievement at having accomplished something in their day and a lack of structure to their days. For some, the solution was to try and find the sense of purpose they felt they had lost since the pandemic began whether through taking online courses or redefining what constituted achievement

> ZOE: it's achieving something, you know, it's easy to, it's just so easy just to go through your day without achieving anything and um, and it's so much better if you have some, some structure and some purpose and achieve something in your day so, um, but

> sometimes just achieving something your day is, is just actually talking to someone or reach out to someone and, and saying, you know, are you okay?

3.5.2 Coping and Resiliency

All participants spoke of ways to manage their wellbeing. For several they felt that their experiences of CHD made them stronger and better able to cope with the adversities of the pandemic. The quote below is from the only participant in the sample who caught Covid.

> ISOBEL: if I I don't acknowledge it and I don't panic everything will be fine. That was my mentality and I think, and I've always been, so when I've been poorly, it's always been 'me panicking is not gonna change it' sort of situation... So, but yeah, normally when I'm poorly I just take it all in my stride and I think again that links back to we've never known any different: surgery, take it in your stride sort of thing.... It's just an event that's happened in my life and again I think that genuinely does stem back to 'we've never known any different'. If it was somebody, you know, who hadn't had an illness like we had and they contracted it, it might be a completely different kettle of fish and how it affected them, but to me it's just another life event

For others, comfort was found in their group identity as people with a CHD diagnosis and social events were set up to facilitate that bond.

> ZOE: It's a really lonely place to be diagnosed with something you know. And in my case, something really rare and unusual without an uncertain, um, sort of life expectancy and prognosis is as a, is a lonely place, so actually just having a place where people can, you can talk about it....you know have your own tribe where people just understand and you can come together and you know you don't need to talk about covid, you can talk about your [hobbies/interests], or whatever it is, it doesn't matter what it is, but just having that those sort of connections

Several other coping mechanisms and strategies were mentioned by participants to maintain their wellbeing including escapism and distraction in the form of books and TV, writing journals and taking up new hobbies. What was particularly striking was that every participant spoke of actively choosing to do these things to support their wellbeing.

> REBECCA: I mean at the moment I'm just sort of, you know, using every possible strategy I've got to kind of keep it all it all at bay

Participants described improvements in wellbeing from talking to friends and family and the importance of their social circles during this time, while others emphasised the importance of being able to do things that they used to or simply being able to be in the physical presence of other people.

> REBECCA: I was able to go into the office about once a week from the middle of July through to December. And that made a huge difference... it just it meant that one day, I was in the same place as real people for like seven or eight hours. And you know, go out at lunchtime and go round the shops in [place name] just get my lunch again and it was just a bit of normality

Many spoke of their need to avoid exposing themselves to others' opinions and behaviours where possible and for one participant, she described how changing her perception of Covid helped her to feel better.

> HANNAH: I just kind of had to view it like a normal virus. It was just a virus at the same time there's just no different to like, we've had some many viruses out there, they don't even have cures and stuff and we've still survived, so I just have to think about it that way

Despite all participants discussing the various cognitive and behavioural coping strategies used, it was unclear for somehow effective these strategies were. Especially for those who lived alone they described the idea of simply coping rather than actually feeling any better.

> REBECCA: well, there's lots of articles you know how to make yourself feel better in the pandemic, and I'm doing most of the things that they say um, and I'm not sure I really, you know, I'm coping, but I'm not really feeling better

> HANNAH: it's just been trying to survive every day …. Take each day as it comes

3.7 Theme 3: Connections

3.7.1 Staying connected

The importance of others is something that has been noted in previous themes but connection, seeking for it, maintaining it, and losing it, was something discussed by all participants. All participants spoke of continuing contact with friends and family and for some participants, they noticed an improvement in these relationships. Several participants spoke about the fact that distance from friends and family suddenly became key as travel became more difficult and was at times not allowed preventing families and friends from connecting in person.

> DANIELLE: in one way heart breaking because she's not just, like even if she lived locally she could go and see her nanny and we could literally shout across the street at her

With the increased difficulties in travel, some participants who didn't have strong local networks of friends or family, spoke of the importance of neighbours and the pandemic being a driving force for them getting to know new people and making new connections.

> REBECCA: I've also got to know some of my neighbours, not very well, but you know enough to chat to, and there's one I've got one, one here I got on Facebook Messenger and one who I've got an email and we occasionally kind of exchange the time of day. Um, so you know, even in this lockdown in this bonk-, bonkers year, you can slightly get to know people.

All participants spoke about using technology to connect during the pandemic whether it was video-calling, social media, or telephone calls. Some spoke of using social media to stay connected with others who had underlying health conditions or CHD more specifically, using these spaces to connect to others like them. Many used these online communities as a source of information and support during the pandemic

> SARAH: The Somerville have also been running um, er socials every fortnight.... fortnightly sessions for anybody who wants to join, and it's quite good because, you know, you can choose to dial in or not but it's just a social, but actually a lot of stuff has come up about what we do in the future, concerns about vaccines or not, um, who's got priority, who hasn't

Others developed creative ways to stay in touch with family and friends setting up group chats, games they could play together online, starting online [hobby] groups and even book clubs.

> LEAH: So I do have really good friends, all my really good friends are back in [place name] (laugh) so we sort of set up a book club erm, sort of a few months in I think. So they're both two really old friends one that I knew from school and one that I met at university. So they didn't really know each other but through that so we've all got to know each other quite well. So that sort of went, sort of every month or every couple of weeks

Many participants however, used outdoor spaces to meet and connect with others as a way of socialising whilst maintaining a feeling of safety despite their online efforts to connect. The driver for these in-person meetings was a feeling shared by all participants; that connecting using technology was not an adequate replacement for connecting with others in-person. For one participant, the inability to hug close loved ones was one of the hardest parts of the pandemic for him.

> MICHAEL: I mean probably the biggest thing out of everything, my daughter obviously is community based, sees people with Covid, I've not hugged my daughter in a year, yeah (laughs but eyes well up), yeah, that's quite an emotional, you know and you know, I mean, it almost brings tears right now, you know it, it's horrible, it's really genuinely horrible

The aspect of touch was not the only difference between online communication and meeting in-person however, as most participants spoke of actively maintaining social distancing whilst meeting with others. It appeared to be just the physical presence of someone else that made the difference.

> ADAM: I think it’s extremely useful um I mean even at work which is a much less personal kind of thing it’s still nice when on those days you go in even if it’s just a meter or two away from somebody you know just to chat or whatever it’s just something about being in a room with somebody that’s nice

Some participants highlighted a lack of appropriate formal support groups that reflected their needs or age groups, with many of the services set up during the pandemic seemingly targeted at older people. This meant that the connections participants had with friends and family became even more important as they were relied upon for practical support such as grocery shopping as well as emotional support as mentioned above. For one participant, this was difficult:

> LEAH: I hate it, I hate relying on other people I really don’t like it at all....Yeah I don’t like relying on other people at all, it really does my head in, I’m very much I like to do things for myself? Or just get someone to deliver it to me like whose job it is.

For others requesting practical support from friends and family, this was made easier by family offering support rather than them having to ask for it.

> ISOBEL: Erm it didn't feel too bad and to be honest me, before we even ask my brother offered so I did as well, I felt like I was putting on him 'cause obviously he lives in [place name]. I didn't, I didn't feel as bad 'cause I'm not had to go on asking. He’d ring and say “I'm going to Dad’s, what do you want?” and then sometimes it’d be like you know “we've got X, Y and Z and I don't need anything”, and other times it be like “oh great, We've got a list”, sort of thing so it was like peaks and troughs but it was beneficial for us to have the support luckily.

3.7.2 Relational strain and loss

All the participants also spoke of strain in their relationships and feelings of loss in relation to their connections with others. For many, it was the opinions and beliefs of relatives and friends who supported anti-vax and conspiracy theories which led to a reduction in contact. For others, it was the divergence in opinion and behaviour around guidelines adherence that caused relational issues.

> ISOBEL: it has an impact because obviously like I say, my in-laws and my sister and brother-in-law they've, they, they're not happy about it, they think we're being over the top, so it's bit of a rift there. Well, at the end of the day, I think they've got to realize that we're not doing it, 'cause my sister-in-law, she said it was just for attention and I was like "it's not for attention, it's for protection more than anything, you know, I'd love to just ignore the rules like you do but I can't".

For those living with others, all spoke of the stress the pandemic had caused on their relationships with those in the house. Some spoke of needing to find their own space such as going on walks alone while others spoke of the difficulty of locking down with loved ones.

> SARAH: Relationships, there's three of us in the house, it is difficult, but I think you know we're all busy in one way or another. And I think you know you go through ups and downs, um lockdown just means you don't get out as much and those occasionally are quite stressful or that quite, they can be, I think they go through phases sometimes, when someone's having a bad day, it can be quite strained, but you know you, you just give them space.

For a lot of the sample, loss of connecting with others was an indirect result of giving up loved activities to keep safe during the pandemic or their workplace mandating working from home so informal office connections were lost. Many spoke of being unable to socialise as they would normally due to government guidance preventing the interactions they usually relied on to see friends. For one participant, even when those guidelines were lifted and she was able to meet with friends again, her time spent shielding had meant she had missed out on-going social events with which resulted in a loss of those friendships.

> LEAH: I hadn't seen anyone for a really long time and I'd been indoors like five months plus. And because everyone else was out and about and seeing each other and having those interactions still, and some of them moved away and went back to their families or the broke up and they all had their little relationship breakdowns. Erm, and because I'm just indoors and they're sort of all seeing each other and doing their thing it was kind of just like 'oh yeah lets just check in occasionally' so a lot of them just sort of dropped away

For some in the sample, they had missed being a part of key family events and the effects of that was palpable. Those who had missed important family moments spoke with sadness whether it was missing birthdays or trips or larger significant moments.

> ZOE: my dad died [when] so I couldn't go to, I couldn't go to [place name] and I couldn't go to the funeral and that was actually really, really, really difficult. Um, my sisters had to do, you know, just not being able to be with them has been um, very difficult…
>
> LEAH: My sister-in-law is gonna have a baby in the next two months and my other friends gonna have a baby and all the things your just kind of like ‘I’m missing all this’

4. DISCUSSION

4.1 Overview

This chapter will review the findings in relation to the research questions and existing literature highlighted in the introduction. Implications and recommendations from this research will be discussed followed by a critical evaluation of the quality of the research. Reflexivity in relation to both the epistemological position of the research and the researcher's own reflexivity will be discussed and recommendations for future research made.

4.2 Returning to the Research Questions

The following research questions were developed to explore the experiences of CHD patients during the COVID pandemic. The first and overarching question, developed from a review of the literature, was how have people with CHD being impacted by the COVID pandemic? More specific questions were developed that reflected the focus and findings of the literature including whether the pandemic influenced participants' mental and physical health during this time and what had made it easier or harder for people with CHD during the pandemic. The final question focussed on what people with CHD want from their NHS services in terms of adaptations and support.

4.3 Summary of Findings

Three themes were constructed from the data: vulnerability, wellbeing and staying connected. The most complex theme, vulnerability, highlighted issues around participants perceptions of being labelled as vulnerable, and the ways in which they had adapted their lives due to the pandemic and the associated cognitive and emotional load. This theme also explored how uncertainty and risk contributed to feelings of threat and a sense of not being safe. Others' attitudes and behaviours also contributed to these experiences with a particular focus on participants feeling 'othered'. The theme highlighted the role of trust, how this applied to different institutions and how it impacted behaviour.

The second theme, wellbeing, focussed on difficulties but also strengths in this area. All participants expressed difficulty with wellbeing at different points during the pandemic with causes including an awareness of participants' own mortality, living alone, and feeling unsafe. All participants spoke of how winter months exacerbated these difficulties. Participants' spoke of how CHD had given them resilience, and the comfort of belonging and getting support from other patients with CHD. All participants spoke of consciously attempting to manage their wellbeing using a variety of coping strategies, the most common being distraction.

The third theme connections, focused on the impact the pandemic had on participants' relationships. This theme emphasised improvements in some participants' relationships, the importance of local relationships and making connections creatively. Factors that caused difficulties in participants relationships were also considered, including the opinions of friends and family having a negative impact, the strain on relationships of those living together whilst shielding, and missing out on key events.

4.4 Relating the Findings to Existing Literature

Mental health and wellbeing was raised by every participant in the sample. Although diagnostic criteria were not applied or sought within this study, participants used words such as 'stress', 'anxiety', 'worry', fear' and 'depressed' to describe their experiences of wellbeing difficulties. Studies measuring pre- and post-COVID rates of wellbeing (either via symptoms or diagnostic labels) have shown a reduction in wellbeing, suggesting that the pandemic has been the cause of some of these issues (Robillar et al., 2020; Sun et al., 2020) and the worsening of wellbeing/increasing in mental illness symptomology has been shown to be greater in those with chronic illness compared to the general population (Sabate et al., 2021).

Participants in the current sample felt it was the pandemic that had had an impact with some reporting experiencing wellbeing issues for the first time, or an exacerbation of previous difficulties. Those who lived alone spoke at greatest length of the wellbeing difficulties they experienced which they linked directly to experiences of loneliness and lack of contact with others, supporting research linking reduction in social contact and impairments to mental health (Benke et al., 2020).. Some literature had also indicated that governmental responses had influenced mental health rates with a prompt response in some countries including support of workers, dissemination of information, pre-existing healthcare and welfare being protective factors for mental health and prognosis despite increase in COVID infection rates (Van der Velden et al., 2020; Wang et al., 2020). Although causal links cannot be made in the current sample, most participants were highly critical of the U.K government's poor response to the pandemic so this may have been a factor here. Other causal factors identified in the literature which were discussed by participants included fear of infection, inadequate supply of basic necessities, financial loss and lack of information from public health authorities (Brooks et al., 2020). This research was conducted on those quarantining, however, given many of the participants interviewed shielded/tried to shield their experiences appear to resemble the experiences of the general population who are in quarantine.

Boyraz et al., (2020) found that perceived vulnerability to COVID increased COVID-related worry and lead to heightened perceived social isolation and traumatic stress. This is an important finding as it suggests that the current participants' perceptions of vulnerability, which were brought about by the labels given to them, may have contributed to worry, feelings of isolation and stress. Many in the sample also mentioned the negative impact of the media coverage with some speaking specifically of death tolls and reporting of fatalities among those with underlying conditions. Participants felt that this reporting had a negative impact on them in contrast to the experimental paper by Silva et al (2021), which found that the content of news (whether death is more or less salient) had no impact on wellbeing but rather fear of death was a strong predictor of poor wellbeing, mediated by anxiety regarding COVID. Fear of death is important to consider as participants spoke of having to face their own mortality during the pandemic which may have also contributed to their difficulties with wellbeing. Silva's study was conducted on the general population, however, so it may be that those who have an increased vulnerability to COVID are more impacted by mentions of death in the media than those who are not.

Furthermore, several in the sample spoke of financial pressures and risk of job loss during the pandemic, another factor shown to impact on wellbeing within the existing literature (Wolfe & Patel, 2021). For the current sample there was an additional complexity of being in the shielding category or not qualifying. Those told to shield were at risk of losing their jobs due to workplaces feeling unable to keep them safe and those not given the protection of the 'shielding' status unable to argue for increased protections at work, making them more vulnerable to COVID-19 infection. Working from home was reported as increasing loneliness for several participants which is supported by past research, though some alleviation was provided by online spaces where workers could socialise (Wang et al., 2021). Additional support was found for research suggesting that if working during the pandemic led to an increased risk of infection it had a negative impact on people's wellbeing but if workplaces had safety measures in place this impact was negated (Bufquin et al., 2021; Tan et al., 2020). In terms of coping, all participants reported actively managing their wellbeing. Distraction and acceptance were the most common mechanisms reported across the sample, supporting the findings of Umucu and Lee (2020). The current findings take this research further in that the decision to manage wellbeing was a proactive and conscious one.

Relationships was also an important theme that was mentioned by all participants in both positive and negative ways. Participants spoke of better relationships with some friends and family during the pandemic and also of the value of informal social support (either practical or emotional) mirroring findings by Philpot et al., (2021) and Park et al (2020). Park et al (2020) also found reports of increased loneliness and decreased feelings of friendship, potentially due to the measures used. Many participants from the current sample also reported loneliness and a loss of friendships. These appeared to be for a variety of reasons including friends and family's views and opinions of the pandemic and their endorsement of conspiracy theories, their lack of availability or understanding of the position of those having to shield or take extra precautions, and due to a loss of time spent together meaning that friendship groups had moved on whilst participants had been shielding at home. Additionally, some participants spoke of a strain on relationships with those they lived with, supporting findings of Eleuteri and Terzitta (2021), with tensions arising due to others in the household continuing to work and so putting those shielding at greater risk, the increased time spent together, members of the family being generally more stressed and the loss of social support/ability to socialise with others. This finding however was not supported by all participants, with some reporting no such difficulties.

Many spoke of avoiding appointments, tests, or procedures due to fears of infection with two participants experiencing health related worries during this time but continuing to avoid medical appointments. This supports Lim et al., (2020) who raised the issue of the secondary impact of COVID-19 for those with chronic conditions. For one participant, previous experiences of hospital staff not taking COVID-19 precautions at the start of the pandemic (before first lockdown) had caused concern, however, for others in the sample who did attend their face-to-face appointments, they found the hospital procedures around infection control containing. All participants had experienced adapted health services with either telephone or virtual appointments taking place in lieu of in-person appointments, and all had experienced a delay in routine treatment (such as check-ups, yearly scans, medication reviews), supporting the findings of several studies including that of Fisher et al., (2020). None in the sample reported difficulties in terms of medication supplies, unlike many groups in the literature (e.g. epilepsy; Hees et al., 2020) although many had to adapt the way in which they accessed their medicine, either using others to obtain medication for them or using online pharmacies. Participants satisfaction with virtual/telephone appointments was variable with many reporting positive experiences with these appointments, especially in terms of quality of appointment but also the time saved travelling to specialist centres. Others highlighted the need for flexibility in type of provision due to the need for scans and certain physical checks. Some participants also expressed a desire to return to face-to-face appointments due to worries things might be missed remotely or from a broader desire to see people in person again.

Existing literature also included studies on health literacy which found that 30% of participants with chronic illness had ‘poor’ knowledge about COVID-19 (Gautam et al., 2021). For the current sample, although they were not explicitly tested on their COVID knowledge, all reported accessing journal articles, following research, contacting medical experts, and looking up government guidance on COVID-19, suggesting potentially good knowledge of the disease. Predictors of ‘good’ knowledge from the research included those living in urban areas, younger age and being better educated (Guatam et al., 2021), however many in the current sample interviewed lived more rurally and were middle-aged suggesting other factors may also play a role in predicting health literacy. In line with Gautam et al., (2021), all participants had a ‘good’ attitude toward safety measures with all of the sample exceeding government guidance of hand hygiene, social distancing and mask wearing in an attempt to avoid infection. Extending these findings further, participants in the sample reported a lessening of their safety measures over time with some returning to shopping in person, visiting others, going away (within the U.K), no longer cleaning shopping items and intermittent mask wearing outdoors.

All participants spoke of having to make their own risk judgements regarding ‘safe’ activities, develop their own safety precautions (often going beyond the government guidance which many found unhelpful/inadequate), monitor their own health, make decisions regarding attending medical appointments and find ways to access basic necessities with professional support available to them at times being considered poor by participants in the sample. All participants spoke of having to proactively contact their heart teams for further advice and guidance and many spoke of the lack of research and knowledge available to them to make decisions leading to a potentially greater loss of freedoms as participants took a cautious approach. These findings support the assertion by WHO (2020) that an additional burden of COVID-19 falls on those with chronic illnesses.

4.4 Implications and Recommendations

This study’s findings provide insight into the experiences of people with CHD during the pandemic with several implications and recommendations arising from them. First, a theoretical implication is that of trust in health behaviours. Within the sample, the theme of trust was mentioned by all, in particular the trust participants had in their consultants (which meant they followed consultant advice and found it containing) but also a lack of trust in media reporting, the government and others which may have been part of the reason some in the sample went beyond government guidance in terms of protective measures against COVID-19. These findings mirror others in the literature investigating trust in the U.K. government and its relationship to adherence of pandemic guidelines. Fancourt et al., (2020) found that, particularly after a chief political aide breached COVID-19 rules, trust in the government’s ability to manage the pandemic and rule adherence decreased. Further commentary was given by Limaye et al., (2020) who argued that the increased reliance on social media during the pandemic, created an environment for misinformation to spread and that the more this information was shared, the more legitimate it seemed. They argued that people increasingly view their peer networks on social media as trusted individuals and that the ever-changing understanding scientists developed on COVID-19 made it difficult to distinguish legitimate from misinformation.

The role of trust in health outcomes and behaviours has begun to be more acknowledged in research literature (e.g. a meta-analysis by Birkhauer et al., 2017). Despite this, trust is not a feature of models of health behaviour (e.g. theory of planned behaviour or health belief model; Taylor et al., 2006). The current findings, along with additional previous literature, suggest that trust may be a factor worth further research in terms of the role it might play in encouraging behaviour change.

An additional theoretical implication was that all participants spoke of technology not being able to replace physical human contact. The relationship between face-to-face contact and wellbeing has been documented in the literature (Nezlek et al., 2002); however, in an increasingly technological world, people are using alternative methods to keep in touch. Research exists that highlights how the use of the Internet to connect with others can increase perceived levels of support and lower levels of isolation and loneliness (Cotton et al, 2013). However, Antonucci et al., (2017) argue that technology, whilst improving our ability to connect to those far away, can lead to increased negativity in interactions. Studies which compare face-to-face interactions with technology-based ones have found that face-to-face social contact is uniquely relevant to people's wellbeing (Macdonald et al., 2021), however, limited explanations as to why were given. The findings in this study add to this growing narrative and suggest that further research into this area would be helpful.

In addition, using technology to conduct medical appointments, given the difficulties in communication highlighted above, may lead to medical issues or deterioration in health being missed, something which was raised as a concern by the participants but also by General Practitioners (GPs). Research has indicated that using technology for medical appointments exacerbates existing language barriers, made rapport difficult to establish, reduced GPs' ability to identify safeguarding concerns and risked technological exclusion (Knight et al., 2021). Participants in the sample raised both the convenience of online appointments particularly for those who had to travel long distances to specialist centres, but also the need for flexibility in appointment type to enable access for all, with most expressing a preference for return to face-to-face appointments.

In relation to government guidance and the response of heart teams around the U.K., the importance of a coherent and unified message was clear. Potential undermining of trust in health professionals occurred due to frustration, uncertainty and worry caused by differing recommendations from different heart teams for the same type of CHD and the prevalent use of online communities and the internet. Since this sample connected to wider networks these inconsistencies in messages were shared widely and became problematic for many. Additionally, many in the sample raised issues of inadequate and impractical government guidance, the lack of protection for anyone at risk but not shielding, and a lack of clear guidance on what activities were 'safe' or 'unsafe' leading many to adopt an overcautious approach, restricting their lives.

It is recommended therefore that services across the country ensure they advise the same recommendations/groupings for CHD patients following the scientific evidence available, especially as most in the sample were reading this research. It is also recommended that the government provide more prescriptive advice on how to risk assess the safety of situations/activities so that those at greatest risk of COVID-19 feel empowered to make more informed decisions. Furthermore, it is recommended that alternative supports are made available for those living with people needing to shield such as providing legal protections to allow family/children to work from home/be home-schooled or financial assistance/furlough to these groups and their workplaces to allow them to continue to support their financial needs. These aspects were all raised by participants within the study as things that impacted their experience during the pandemic. A last recommendation relates to providing protections and guidance for those who fall into the highly vulnerable category so that they can seek adaptations to their working life, enabling them to earn without greater risk of infection. Additional support could be given to workplaces who have vulnerable people in their employ so that employers know how they can maintain a safe working environment. Financial incentives could be introduced to encourage workplaces to invest in safety protocols which would not only protect these groups but also potentially reduce staff absences and sick leave due to lower transmission of COVID at work.

An additional but related point to the above, was the use of and language of groupings used to identify those at greater risk of COVID-19. While all participants identified that they may be more susceptible to COVID-19 than others without a heart condition, many disagreed with the language used to label them, found this labelling damaging or upsetting. Participants felt othered by both the label used and others' reactions to this grouping and subsequent narrative of them being burdensome. It is recommended that governments and institutions think carefully about the language they use when attempting to disseminate information about susceptibility, talking to groups about the labels they might prefer. Institutions should also take responsibility for the narratives around those who may be more susceptible and think about how to explain the measures put in place in a way that does not leave these groups scapegoated and blamed.

Further implications arose around the types of support available for this group during the pandemic. The lack of available local support for people in this sample and the lack of understanding of the needs of this group by local councils, government, non-specialist NHS services and wider support services meant that opportunities to provide avenues to improve their experiences of the pandemic were missed. The sample also raised the value of the NHS continuing to offer flexible services in terms of online, telephone, or face to face appointments beyond the pandemic as this flexibility made treatment at specialist clinics more accessible for some but also respected the need for face-to-face assessments and scans for others. All participants spoke of a desire for more regular contact from their heart teams, especially providing updated advice and information as things changed over the course of the pandemic.

Recommendations stemming from this include training and awareness of key stakeholders such as local councils, charities and wider NHS staff on the needs of CHD patients, the continuation of flexible appointments giving choice to patients and more regular contact from teams to their patients. One participant even highlighted how technology such as e-mails and social media could make more regular contact cheap and easier to achieve.

A further implication from this study was the finding that all participants reported struggling with their wellbeing at some point during the pandemic, regardless of whether they had previous histories of mental health difficulties. These difficulties were especially focussed on by participants who lived alone compared to others in the sample who lived with relatives and partners. Many causes were identified by participants for their perceived wellbeing difficulties including ongoing issues of feeling unsafe and fear of mortality, the impact that the duration of the pandemic was having, use of social media and being stuck at home. All participants spoke of winter months being especially difficult to manage. All participants spoke of ways they were managing their wellbeing and informal social support, escapism and finding a sense of purpose were key strategies shared by most.

In terms of recommendations, it is clear that regular check-ins on mental health over time regardless of initial reports of ‘wellness’ are vital for professionals working with this group as wellbeing fluctuates over time. Special attention should also be paid over winter which all participants spoke of as being harder and services should consider providing additional resources and support during these months. In addition, many participants spoke of the comfort they experienced being able to connect to others with similar health problems, so services could consider facilitating peer-to-peer communication and support for these groups.

In terms of the feasibility of these recommendations, there are some already taking place (e.g. flexibility in appointment types) and others such as increased contact from heart teams, check-ins on patients mental health by professionals and facilitation of peer-to-peer support groups would be relatively straightforward and low cost to implement. Changing and updating government guidance on how to risk assess situations for likely COVID infection would also be easier to implement now given how much we now know about the transmission of the disease. Similarly, lessons learned from the current pandemic around the language used to disseminate information about susceptibility and how to explain emergency measures put in place would be able to be added to future pandemic related policy to prevent these issues arising again. It should also be noted that in the face of new diseases where scientific evidence is lacking, it may be difficult to ask services across the country to provide blanket rules for all patients and patients own individual circumstances (especially in relation to the variable nature of CHD presentations) should be discussed with their consultants. However, agreed upon generic guidance could and should be offered with a more cautious stance adopted until further information became available.

The complexity in implementation, stems from potential cost and where the funding would come from. Training for stakeholders on CHD would be straightforward to implement but would require significant financial investment and issues around who would take responsibility for this training would need to be dealt with. Ensuring further supports are offered to those at greatest risk of severe illness and death including financial packages for individuals and workplaces and legal protections for family to enable working from home would be complex and costly for the government to implement and therefore less likely to happen. Given the large and likely increasing numbers of people living with chronic health conditions however, this investment should be considered in future pandemic planning to prevent significant losses to the workforce and the subsequent impact of lack of spending on the economy and the increase of those on benefits.

4.5 Future Research

This study has demonstrated the importance of understanding the needs of those with chronic illnesses who have increased susceptibility to COVID-19. As those with CHD constitute only one such group, further research on the impact of the pandemic on those most vulnerable would help get a better understanding of how to improve government and NHS policy and planning to develop better quality pandemic protocols moving forward. This research should focus on different conditions and acknowledge the heterogeneity of those with chronic illness, rather than trying to place them all into a single homogeneous group. Participants in the current study spoke of frustration at being placed in risk categories that didn't seem to reflect their current health status and the lack of acknowledgement of individual circumstance to develop more nuanced and tailored risk guidance. Research should also focus on the needs and experiences of this group now that the U.K. has moved into the 'Living with COVID' phase of its pandemic response and what this means for those with chronic illnesses and how they live their lives.

Further research could also examine/investigate ways to challenge and prevent the 'othering' of those with chronic illness as the response of others (including members of the public and institutions) toward those with chronic illness during the pandemic, was a source of stress for this sample. There is an extensive body of literature on ingroup/outgroup behaviours, prejudice reduction and intergroup relations, and its application here would be invaluable. Research questions could focus on how to reduce negative attitudes and prejudice towards those with chronic illness and how to implement public policy in a way which reduces differences between perceived 'healthy' and 'not healthy' groups. Additional research could also look at the role of language and how the use of labels such as 'extremely clinically vulnerable' and 'highly vulnerable' may influence people's perceptions of themselves and other's perceptions of them.

4.6 Critical Evaluation

How to assess the quality of qualitative research and whether a single set of criteria is appropriate given the heterogenous nature of qualitative approaches and philosophies is a topic which has received significant attention in the literature (Yadav, 2021). While no consensus currently exists on how best to evaluate this type of research, for the purposes of this thesis, the “Big Tent Criteria” by Tracy (2010) will be used as it is applicable to the current research paradigm and clear guidelines on how to rate qualitative research within the criteria outlined have been given.

4.5.1 Worthy Topic

Tracy defines a worthy topic as one that “is relevant, timely, significant and compelling” (2010, p.2). The current research has worth not only because of its timeliness in relation to the COVID-19 pandemic but because of its contribution to the literature. Despite a vast amount of research into COVID-19, minimal research has been conducted on how the pandemic impacted on those with chronic illnesses, only one study at the time of the scoping review had conducted qualitative research in this area and no research had been conducted on how those with a CHD diagnosis experienced the pandemic. Although some of the current findings simply supported existing literature, the research also added to the current knowledge base in several ways highlighting the different ways in which the pandemic uniquely impacted this group. Examples of this include the impact of labelling people as extremely or highly vulnerable, the complexity of ‘shielding’, views on the dialogues around herd immunity and the different ways in which their lives had changed.

4.5.2 Rich Rigor

Tracey (2013) argues that rigor relates to the appropriateness of the research in terms of methodology including things such as the theoretical goals of the research, the procedures used for data collection and analysis and volume of data. In terms of the current research, chapter 2 outlines in detail the ontological and epistemological positions of the researcher and puts forward an argument for the type of data collection and analysis used. There are some issues with the research in terms of the amount of data collected. Although there are no rules for how much data is needed, Weller et al. (2018) suggest 10-12 interviews are needed to reach data saturation. However, the project was advertised across social media including on the Somerville Foundation social media pages and due to limitations of time for the project, more participants could not be sourced. Despite this, qualitative research has been conducted with smaller samples than those included here, especially if the data is unique or rare (see Scarduzio & Geist-Martin, 2008) which given the current literature on this topic, could be argued to be the case. The way in which the data was transformed and analysed is also explained in detail throughout the thesis and a clear outline, taken from Braun and Clarke (2006) is highlighted in chapter 2.

4.5.3 Sincerity

Tracey (2010) argues that sincerity is achieved in research through self-reflexivity, honesty and transparency all of which are present in this thesis. The researcher's background and biases were shared in chapter 2 and are discussed again below in the current chapter and throughout the thesis, the researcher has been transparent about how the research was conducted. Furthermore, limitations of the research were shared and acknowledgements made to all those who participated in the research including supervisors, participants and supportive colleagues.

4.5.4 Credibility

Tracy (2013) states that credibility is achieved through thick description, crystallization or triangulation, multivocality and member reflections. Taking each of these in turn, thick description refers to going beyond the data and drawing out tacit knowledge. The researcher attempted to do this through the development of codes and later themes and subthemes, trying to capture unarticulated and common threads between interviews. It is important however to identify that the researcher in this instance was a novice to qualitative methods and so many opportunities to develop and probe for tacit knowledge may have been lost in both the interview process and later analysis.

Crystallisation or triangulation refers to the gathering of multiple types of data or utilising co-researchers to look at data through multiple lenses. Multivocality and member reflections can be ways to achieve this by highlighting differences between participants' narratives or engaging participants in data analysis, asking for their feedback. Where applicable, the researcher did highlight differences in viewpoints throughout the analysis as this approach was compatible with the critical realist position of the research. Due to the timeframe and a gap in the research project between data collection and analysis and subsequent write up, it was not possible to contact participants to engage in the process of member checking/reflection (although this technique to improve the quality of data has been debated; Cohen & Crabtree, 2008) and it was not possible to engage in peer review or auditing processes. This calls into question the credibility of the findings. The researcher has attempted to mitigate this by being transparent throughout the thesis regarding the process of the research. Examples of reflective diary extracts, transcripts, initial codes, themes and how these were reviewed, have all been included. The project supervisor also reviewed parts of transcripts, a sample of codes and the final themes for comment during this process.

4.5.5 Resonance

Resonance refers to the impact the study has on its audience (Tracey, 2013). Given the topic of the research and that the readers are likely to have their own experiences of the COVID-19 pandemic, the transferability of the research is significant. If readers have compared the research findings with the own experiences, they have transferred these findings. Whether the research enables readers to 'feel with' the participants is something that cannot be commented by the author, but it is hoped through the careful selection of quotes from transcripts that this was achieved.

4.5.6 Significant Contribution

It is important that research extends the findings or adds to a body of research in a significant way (Tracey, 2013). The current study does this in the form of conceptual development, by offering new understandings, particularly around the role of trust in health behaviours (see above). The current research has also developed findings from the main body of literature on people's experiences of the COVID-19 pandemic adding insight and offering potential explanations from some of the relationships identified within the existing literature such as potential causes of the worsening of mental health. The research also draws attention to a marginalised group, highlighting the unique impact the pandemic has had on those with chronic illness to give a voice to those often overlooked.

4.5.7 Ethical

Throughout the research, ethical practise in line with BPS standards, was maintained. The research was designed to cause minimal harm (distress may have been experienced when talking about topics but steps were taken to mitigate this), no participants were deceived, all were able to give informed consent to participate and the researcher took steps to ensure participants' privacy and confidentiality. This last point can be particularly difficult in qualitative research, especially when interviewing a sample from a small population. Some extracts that may have provided better support for certain points were not used to ensure participants could not be identified by their heart teams and key demographic data was not reported (including participants specific diagnoses, and where in the U.K. they resided) to protect their identity.

The researcher also prioritised participants' wellbeing throughout the interviews, stopped when participants became upset, reminding them of the right to withdraw in these moments and gaining additional consent to proceed and providing signposting to support services in the debrief. Relational ethics were also considered throughout the research with the researcher being mindful of their role and the impact they could have on participants, the importance of being respectful of participants as people and not viewing them simply as useful data and ensuring that the findings of the research are appropriately disseminated to reflect the value of participants time and ensure that their contribution and efforts are not wasted.

4.5.8 Meaningful Coherence

Tracey (2010) refers to meaningful coherence in qualitative studies stating that they should "(a) achieve their stated purpose; (b) accomplish what they espouse to be about; (c) use methods and representation practices that partner well with espoused theories and paradigms; and (d) attentively interconnect literature reviewed with research foci, methods, and findings” (p.848). For the purposes of the current study, the research questions initially developed were answered through the data gathered and themes constructed. The methods and practices used throughout the research were appropriate for the epistemological and ontological position of the researcher and the findings constructed linked back to existing literature.

4.7 Reflexivity

It is important to consider how my role as the researcher may have influenced and shaped this thesis and how the thesis has shaped me, fitting with my critical realist approach (Silverman, 2001). That researchers question their methodological decision making and consider how their epistemological positions impact the research and therefore the knowledge derived from it is an important part of the reflexive process (Dowling, 2008).

To address this, it is essential to highlight that my own background in research and indeed the bulk of my learning in terms of methodology and ontology has been largely quantitative and positivist. The education I was given was largely disparaging of qualitative approaches, a position I think that is ingrained in society and reflected in several institutions such as the NICE guidelines ranking of ‘gold standard’ research. UEL provided my first thorough teaching experience of epistemology, ontology and qualitative methodology and motivated me to complete my own qualitative work to learn and gain this experience.

This meant that for this project, I was a novice and I felt very lost and confused for most of the process, something that was new to me as I have a historically strong background in research. My background and newness to this approach may have meant that I missed things in the planning, and development of the research project and during interviews and data analysis that a more experienced qualitative researcher would not have. Furthermore, due to my historical quantitative bias, I may have been overly looking for patterns in data rather than difference and seeking to generalise where it was not appropriate.

It may have been due to my novice position that I selected thematic analysis as my methodology as it felt more accessible and straightforward then other approaches. As thematic analysis is not linked to a specific theoretical approach to qualitive research, so the research questions and epistemological position were more influential in terms of the themes developed. Other approaches however could had shed light on other key areas of the data. For example, all participants discussed the ways in which the government, media and others spoke of those in more vulnerable groups and how this new labelling of ‘extremely clinical vulnerable’ and ‘highly vulnerable’ impacted on their identity. Using discourse analysis would not only fit within the framework of critical realism but would have provided a very different analysis looking at the language used and how it constructs our social reality.

Having had opportunities to think and develop myself as a researcher, I now identify as a critical realist (a western philosophical position) rather than a positivist however this new position also biases my work. By even asking the question ‘how have people with CHD being impacted by the COVID pandemic’ I was assuming that a CHD diagnosis would shape people’s experiences of COVID-19 and that it was this health condition, rather than other differences such as socio-economic status, age or gender for example, that would be the driver behind people’s experiences. An additional bias in the subsequent research questions on mental and physical health and the experiences of NHS services during this time should also be considered. Although these questions were designed to reflect the existing body of literature and therefore draw out potential difference in the experience of those with CHD, it is important to consider why mental and physical health was a focus of research to begin with.

Links between physical and mental health are widely accepted in the literature and it is reasonable to assume both would be of interest in a global pandemic, however the focus of these topics in the literature reflected that of personal responsibility for health (i.e. focus on individuals exercise, eating patterns, coping strategies). The literature largely ignores social inequalities that drive physical and mental health issues and on reviewing my own questions given in the interviews, I have found this bias toward personal responsibility. What answers I would have gotten if I had acknowledged these social inequalities and factors more in my questioning remains unknown.

Moving on to focus more on how my personal roles, beliefs and experiences may have impacted on the work, it is important to acknowledge my group memberships as a professional white woman from a western culture. My own drive to conduct research reflects my value of science and the quest for knowledge and my choice of research topic reflects my desire to use my inherent power given some of my group memberships, to provide a space for marginalised groups to have a voice. However, the power I hold/held when conducting the research may have influenced the participants who may have felt unable to deviate far from the questions asked or explicitly state that the topics, I developed were irrelevant or my position an unhelpful one. My own role as a trainee clinical psychologist may have also influenced my preoccupation of wellbeing issues in terms of research focus as it is an area I am passionate about.

Additionally, during the course of this research, my family found ourselves needing to shield due to my husband’s cancer diagnosis. Although a temporary measure for the duration of his treatment (unlike for the participants), he too was considered extremely clinically vulnerable and so we were having to make similar decisions and choices to those of my participants. This event occurred in-between data collection and subsequent transcription/analysis so although this personal experience did not impact on the research design or interviews, it may have influenced the later analysis. In fact, it is key to note that prior to this personal event, I had minimal experience of chronic illness or ill health and so my ignorance on this subject will have influenced and potentially resulted in lost data and opportunity.

5. FINAL SUMMARY

This research has attempted to promote the voices of those with CHD and to better understand how their lives have changed since the start of the COVID-19 pandemic. Semi-structured interviews illustrated how significant the pandemic has been for this group in terms of the adaptations they have had to make to their lives to ensure their own safety, the impact of being labelled as ‘vulnerable’, and how the behaviours and attitudes of others have led to increased feelings of unsafety. Furthermore, the research highlighted the role of trust in their relationships with services (or lack thereof), the changes in their wellbeing and physical health since the beginning of the pandemic, how their relationships with others have been affected and how responses from government and institutions have helped or hindered them during this time.

This thesis provides novel contributions being one of only two qualitative studies looking at the experiences of people with chronic illness during the pandemic in the literature and the only one to focus on those with CHD. The findings have suggested how important it is to provide adequate guidance to those more susceptible from COVID-19 in terms of how they can keep themselves safe and to provide more support to those around them to ensure they are not put at further risk by those they live with. The research has also highlighted the importance of clear communication between professional bodies and patients and the importance of a united message, especially given the connectedness of patients through the internet where different messages can be spread and cause confusion and concern. Furthermore, it has been highlighted that workplaces may need support and incentives to ensure safe working environments for those at greater risk from COVID-19 and that policy should include protections for those who fall in the ‘highly clinically vulnerable’ groups but do not need to shield. Lastly, it was highlighted how patients appreciated flexibility in their medical appointments (i.e. telephone, online or in person) but that more support services are needed for this group, especially for wellbeing and that services should, where they can, reach out to their patient populations providing much desired contact.

This study has also highlighted the negative attitudes toward those with chronic illness and the impact that this can have on those affected by them. More needs to be done to educate and challenge these attitudes at all levels of society to improve the quality of life of those impacted by chronic illness. Further research is also needed on other groups who fall under the umbrella term of ‘chronic illness’ so that policy and protocol can be tailored to better suit the needs of all. As a final point, additional research is needed into how those with chronic illness are impacted upon now, given the move to ‘Living with COVID’ within the U.K. What this means for those who are more susceptible to severe illness and death from COVID-19 and how their lives may now be changed for the foreseeable future is imperative to understand not just from a moral and ethical position but also in terms of maintaining the mental and physical health of these groups.

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APPENDIX A: Summary table of scoping review papers

Authors	Sample	Country	Design	Key Findings
Addis et al., 2021	413 chronic disease patients (hypertension, diabetes mellitus and chronic heart disease)	Ethiopia	Cross-sectional, using quantitative standardised questionnaire (Impact of Event Scale-Revised)	22.8% of sample reported the pandemic had mild-severe psychological impact
Consonni et al., 2021	67 participants with small fibre neuropathy, chronic migraine and chronic pain and 13 controls (healthy family members)	Italy	A battery of quantitative standardised questionnaires	Those with chronic disease reported lower quality of life, physical health and higher catastrophising attitude toward pain than control group.
Hees et al., 2020	399 participants with epilepsy	Europe, Brazil and North America	A battery of quantitative standardised questionnaires (HADS, PHQ-9)	4.9% had difficulty accessing medication due to covid-19, 50.4% screen positive for anxiety, 46.9% screen positive for depression. Females and those with financial problems were associated with depression and anxiety.

Da Silva at el., 2020	249 participants with chronic disease (hypertension, hypercholesterolemia, obesity and diabetes)	Brazil	Cross-sectional, participants interviewed using a variety of self-report measures and quantitative standard scales	71.5% of sample did not meet minimum physical activity requirements and 62.7% spent 4 hours or more sitting per day
Hyland & Jim, 2020	15 participants with lung cancer	USA	Qualitative interviews, inductive grounded theory	Six key thtmes: Cancer as the primary health threat, changes in oncology practice and access to cancer care, awareness of mortality and perceptions of risk, behavioural and psychosocial responses to covid-19, sense of loss/mourning and positive reinterpretation/greater appreciation for life

Irmak et al., 2020	185 participants with chronic disease	Turkey	Cross-sectional design using a battery of quantitative standardised measures (GDS-SF, MMAS-8 and questions added by researchers with quantitative responses).	65.9% reported that regular health checks were negatively impacted and 42.1% continued to comply with diet program, 21.7% complied with exercise program and 74.6% complied with their medication
Gonzalez et al., 2021	310 participants with chronic obstructive pulmonary disease	Spain	Telephone surveys with standardised scripts and measures (mMRC dyspnea scale, COPD CAT)	62% decrease in the number of COPD exacerbations was observed comparing before and during covid-19 lockdown and 74% reduction in COPD health care costs
Umucu & Lee, 2020	269 participants with chronic illnesses ()	USA	Cross-sectional survey using quantitative standardised measures (PSQ-8 adapted to covid, brief COPE, PERMA-profiler, PHQ-4)	Coping strategies uniquely accounted for significant proportion of variance in well-being. Acceptance and distraction most common coping strategies. Participants with higher levels of perceived stress used greater levels of self-distraction, denial, substance use, behavioural disengagement, venting, planning, religion, and self-blame.

Sabate et al., 2021	232 participants with irritable bowel syndrome and 72 without	France	Online survery using quantitative standardised measures (HADS) and questions developed by researchers	Significant more participants with IBS reported significant anxiety and depression, and lower levels of quality of life compared to controls. 19.9% participants with IBS reported worsening of symptoms
Pettinicchio et al., 2021	1027 with chronic illness (asthma, cancer, chronic kidney disease, chronic respiratory or lung disease, diabetes, hypertension, heart disease, immunocompromised or obesity)	Canada	Quota-based online survey using quantitative questions developed by researchers	Financial difficulties due to covid-19 were associated with increased levels of anxiety, stress, and despair. Participants most concerned with getting infected with covid-19 and those who reported increased loneliness were more likely to report increased anxiety, stress, and despair
Saqib et al., 2020	181 participants with chronic dieases (hypertension, mental health issue, diabetes)	Pakistan	Semi-structured questionnaire with questions developed by researchers	45% reported lockdowns had impacted their health, 53% and 42% respectively missed routine medical check-ups and testing and 66% were unable to complete their daily exercise
Wu et al., 2020	563 participants with chronic autoimmune disease systemic sclerosis	Canada, USA, UK, France, Spain, Mexico, and Australia	Cross-sectional survey using quantitative standardised measures and a new standardised measure (PHQ-8, PSS,PROMIS) developed by authors	Support found for use of COVID-19 Fears Questionnaire with good internal consistency reliability and convergent validity.

			(COVID-19 Fears Questionnaire for Chronic Medical Conditions)	
Chudasama et al., 2020	202 healthcare professionals (HCP) on patients with chronic illnesses	Europe, Asia, South America, Africa, North America and Oceania	Quantitative questionnaire developed by researchers	14% HCP continued face-to-face appointments. 67% HCPs rated moderate-severe effects on patients due to covid related healthcare service changes. 80% reported worsening of patients mental health
Xia et al., 2020	119 participants with Parkinson's and 169 controls	China	Cross-sectional questionnaire based including quantitative standardised measures (PSQI, HADS) and questions developed by researchers	22.7% and 21% of the Parkinson's participants experienced depression and anxiety, respectively. 68.9% of participants with Parkinson's suffered from sleep disturbance. All scores were significantly higher than those of healthy controls.
Polenick et al., 2021	705 participants with chronic illnesses	USA	Cross sectional online survey. Quantitative questionnaire developed by researchers	Increased worry re covid-19, financial strain and greater loneliness predicted higher levels of sleep disturbance

Addis et al., 2021	413 participants with chronic illnesses (hypertension, diabetes mellitus, chronic heart disease, kidney disease, respiratory disease, HIV/AIDS)	Ethiopia	Cross-sectional questionnaires using quantitative questions used in other studies on covid-19 and developed by researcher	69.7% participants had moderate-good knowledge about covid-19and 81.4% had good attitude towards covid-19 (assessed by safety measures followed). Younger age groups, those in urban areas were predictors of moderate-good knowledge.
Ramezani et al., 2021	410 participants with multiple sclerosis	Iran	Cross-sectional questionnaires using quantitative standardised measures (HADS, Corona Fear Questionnaire) and questions developed by researchers	39.3% and 31.2% of participants had symptoms of depression and anxiety and those with these symptoms reported greater levels of fear regarding covid-19 than those without symptoms.
Moncorps et al., 2021	93 participants with chronic fatigue syndrome (CFS) and 99 participants with ‘other recognised diseases’	France	Cross-sectional questionnaire using quantitative questions developed by researchers	CFS patients use less coping strategies focussed on social support and problem solving compared to participants with other recognised diseases
Huynh et al., 2020	522 participants with chronic illnesses	Vietnam	Cross-sectional questionnaire using quantitative questions developed by researchers	72.8% and 62.1% participants got covid-19 information via television and social media respectively. 68.4% had comprehensive/sufficient knowledge of covid-19. Specific gaps in knowledge were found at varying rates throughout sample.

Gautam et al., 2021	412 participants with chronic illnesses	India	Cross-sectional questionnaire based using quantitative measures (HLS-EU-Q47) and questions developed by researchers	65.8% participants had insufficient health literacy and only 55.1% had median levels of covid-19 awareness and 45.1% engaged in preventative behaviour
Cransac-Miet et al., 2020	195 participants with chronic coronary syndrome	France	Cross-sectional telephone interviews using qualitative and quantitative questions developed by researchers	All participants followed lockdown rules, 3% stopped taking prescribed medication, 45% experienced a reduction in physical activity, 26% reported an increase in tobacco use and 24% experienced increase in weight
Koh et al., 2021	461 participants with epilepsy		Cross-sectional questionnaire using quantitative standardised measures (HADS, QOLIE-31) and questions developed by researchers	13% participants experienced worsening of seizures, 26% found it difficult to reschedule medical appointments 28.9% were afraid of going to emergency units and 11.5% had adjusted medication to avoid running out. 27.6% and 18.8% reported abnormal levels of anxiety and depression respectively
Schwartz et al., in press	109 participants with chronic illness	USA	Cross-sectional questionnaire developed by researchers	54% healthcare services were discontinued and participants experienced loss of healthcare services despite regardless of financial, social and educational privilege

Vogel et al., 2020	1019 participants with multiple sclerosis	USA	Cross-sectional questionnaire using quantitative questions developed by authors	11% participants reported difficulties in accessing medicine. 64% participants cancelled or postponed medical appointments. COVID-19 was rated by participants as not having a major negative impact on diet, exercise, or personal finances
Browne et al., 2020	35 participants with hypertension	Brazil	Observational study	Participants had an increased amount of time spent engaging in sedentary behaviours, reduced number of daily steps and spent less time engaging in physical activity
Meza-Palmeros, 2020	20 participants with chronic illnesses	Mexico	Ethnographic research	Focussed on understanding participants behaviours in dangerous situations, especially looking at relationships between the population and health authorities. Medical discourse was shaped by media.
Kalron et al., 2021	120 participants with multiple sclerosis	Israel	Cross-sectional survey with questions developed by researchers	50.8% of participants reduced or stopped physical activity and 31.7% reported a decline in their physical fitness.
Radtke et al., 2020	327 participants with cystic fibrosis	Switzerland	Cross-sectional questionnaire with questions developed by researchers	45% participants reduced physical activity due to closed training facilities, lack of motivation and cancelled supervised training. Half of

				planned outpatient appointments were postponed or cancelled.
Bala et al., 2021	108 participants with diabetes	India	Cross sectional with quantitative standardised questions (SDSCA, K10) and questions developed by researchers	75% participants engaged in healthy eating plan, 50% participants completed 30 minutes daily physical activity, 85% had not tested blood sugar levels, 83% did not check their feet
Fisher et al., 2020	763 participants with type 1 diabetes (T1D) and 619 participants with type 2 diabetes (T2D)	USA	Cross sectional with quantitative questions developed by researchers	40% participants reported medical appointments had been cancelled or postponed, 45% reported lower satisfaction with telephone/online appointments, a third of the sample reported concerns accessing food to maintain their normal diet, and 86.6% of T1D and 78.4% T2D reported increases in stress
Mueller et al., 2021	52, 844 participants with epilepsy	Germany	Audit of routine clinical data	An increase in prescriptions was recorded prior to initial lockdown as patients stocked up on medication as recommended by medical societies. Fewer prescriptions were written for new patients with epilepsy hypothesised to be due to reduced medical care for this group.

Assenza et al., 2020	456 participants with epilepsy and 472 controls	Italy	Cross sectional using quantitative standardised measures (BDI-II, GAD-7, PSQI) and questions developed by researchers	Participants with epilepsy had more severe depression and more severe anxiety symptoms than participants without epilepsy but no difference was found between the two groups regarding sleep disturbance. 1 in 5 participants reported worsening of epilepsy symptoms

APPENDIX B: Interview Schedule

Preamble

- Introductions
- Purpose of interview
- Consent, confidentiality, right to withdraw
- Any questions

Demographic information (identify how many high risk groups they belong to), who they live with, severity of illness

Physical Health Management

- How do you live with CHD. Has this changed during the pandemic? If so, how?
- What was important for you before the pandemic and what is important for you now?
- How has life changed for you since the pandemic began?

- Can you tell me how you have been managing your physical health during the pandemic- has anything changed from what you would normally be doing and if so how?

- Has anything made it easier or harder to manage your physical health during this time?

- Have you noticed any changes to your physical health during this time? What do you think the cause of this change could be?

Ideas from consultation:

- Guidance on exercise, diet, other preventative activities
- Medication compliance (ability to get medicine safely)
- Guidance VS COVID safety (going out to exercise/gym over staying in)

Mental Health

- Have you noticed a change in your mood or how you feel during this time? If so, in what way?

- Do you feel that your mental health has been impacted in anyway?
    - Prompt- For example do you feel more stressed?

Ideas from consultation:

- Mood
- Feelings (anxiety, isolation, abandonment, guilt versus legitimate entitlement, overwhelmed, uncertainty- is it safe for me to eat out, gym etc, hope)
- Post-diagnostic care

- Therapy
  - On video
  - At home (not all homes have privacy, supportive housemates, physical space, no escape- can't leave issues at therapist and come home)

Services

- What has been happening in terms of access to your services?
  - Prompt: Have your routine/regular treatments been ongoing? Have you got scans booked? Have you had appointments cancelled?

- Have you had any contact with your services since the pandemic? How did you find this contact? What method of contact was it (telephone, online, email)? How do you feel about the move to online/virtual contact with services?

- How would you like future contacts to be managed?
  - Prompt: Online, over the phone, in person but with safety measures in place?

Things make it easier/harder

- What has made this period of time easier/harder for you?
  - Prompts- have you been able to access essential services (food, medicine)? Social Media (reading news, support from friends remotely)? Online communities? Community support groups (how has it felt accessing these services, stigma? have they been useful/accessible/continued throughout)? Charities? Financial/work situation (supportive/not so)? Religion?

APPENDIX C: Ethics Application (with appendices removed- see other relevant appendices below)

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL
FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2019)

FOR BSc RESEARCH
FOR MSc/MA RESEARCH
FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Completing the application

Before completing this application please familiarise yourself with the British Psychological Society's Code of Ethics and Conduct (2018) and the UEL Code of Practice for Research Ethics (2015-16). Please tick to confirm that you have read and understood these codes:

☒

Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.

When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.

Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).

Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

The participant invitation letter ☒

The participant consent form ☒

The participant debrief letter ☒

The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.

A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.
Included or ☒

Not required (because no participation adverts will be used) ☐

A general risk assessment form for research conducted off campus (see section 6).
Included or ☐

Not required (because the research takes place solely on campus or online) ☒

A country-specific risk assessment form for research conducted abroad (see section 6).
Included or ☐

Not required (because the researcher will be based solely in the UK) ☒

A Disclosure and Barring Service (DBS) certificate (see section 7).
Included or ☐

Not required (because the research does not involve children aged 16 or under or vulnerable adults) ☒

Ethical clearance or permission from an external organisation (see section 8).
Included or ☐

Not required (because no external organisations are involved in the research) ☒

Original and/or pre-existing questionnaire(s) and test(s) you intend to use.
Included or ☐

Not required (because you are not using pre-existing questionnaires or tests) ☒

Interview questions for qualitative studies.
Included or ☒

Not required (because you are not conducting qualitative interviews) ☐

Visual material(s) you intend showing participants.
Included or ☐

Not required (because you are not using any visual materials) ☒

Your details

Your name: Claire Russ

Your supervisor's name: Kenneth Gannon

Title of your programme: Doctorate in Clinical Psychology

UEL assignment submission date (stating both the initial date and the resit date): May 2020

Your research

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and details of your proposed research.

The title of your study: The experience of the COVID pandemic for people with Congenital Heart Disease (CHD) in the U.K.

Chronic illness can be defined as any illness that persists for a long period of time, requiring continuous support, care and treatment at least periodically to manage symptoms, and has no cure (Dubouloz, Paterson, King, & Ashe, 2010). Congenital Heart Disease (CHD) is an illness which falls into this category because, although it can be well managed, there is no current cure. Those with a diagnosis of CHD have been identified as being more at risk from COVID-19 (more likely to experience serious symptoms requiring hospitalisation or resulting in death) particularly if they have any of the following; Fontan circulation, very low oxygen levels, a significant valvular disease, if they require medicine for their cardiac functioning, have pulmonary hypertension, have had a heart transplant or have a diagnosis of other common comorbidities such as diabetes, hypertension, kidney or lung disease (Guys and St Thomas'Foundation Trust, 2020).

Within the medical literature for chronic illness, the idea of self-management (decisions resulting in behaviour performed by individuals to reduce the impact of or prevent symptoms related to their illness; Audulv, Norbergh, Asplund, & Hornsten, 2009) is seen as key to reduce costs to health services and improve patient's prognoses. These self-management decisions can be negatively impacted by lack of social support, resource factors (finance, access to facilities), and poor mental health. In light of a pandemic in which 1 in 10 businesses report they are at moderate or severe risk of insolvency, 39% adults in the UK reported their well-being has been negatively impacted, and the number of people claiming universal credit rose to 2.7 million in July (117% increase since March 2020; Office for National Statistics, 2020) it would be reasonable to question what impact this has had on those with diagnosis of CHD and their ability to manage both their physical and mental health. Although community support groups were put in place locally to support those in high risk groups, it is unclear how effective these have been or whether people accessed them. Literature has shown that those with chronic illness face real stigma and often experience anticipated stigma (the belief that they will experience prejudice or discrimination from others in the future) which can impact on their physical and mental health and prevent them from accessing services (Leventhal et al., 2004)

Your research question:

How have people with CHD being impacted by the COVID pandemic?
Has the pandemic influenced their mental health and physical health during this time?

What has made it easier or harder for people with CHD during the pandemic?
What do people with CHD want from their NHS services in terms of adaptations and support?

Design of the research:

As this research is exploratory, a qualitative design will be used. Semi-structured interviews will be used to enable the participant freedom to discuss and change the course of the interview based on what they feel is important to share or highlight. A critical realist position will be taken for this research as it argues that an objective reality exists (e.g. the COVID pandemic) but our own realities are influenced by our culture, social and psychological factors.

Participants:

20 participants will be recruited to take part in the study. Inclusion criteria are as follows: they must be between 18 and 65 years of age and have a diagnosis of congenital heart disease, they must speak English sufficiently well to consent and participate in the study, they must have access to a computer and the internet in order to join the virtual interview, they must currently reside in England and have lived in England during the COVID pandemic.

Recruitment

Participants will be recruited through social media and through word of mouth. Information regarding the study will be posted on Facebook in a group for people with CHD. Those who wish to participate will be able to use the information provided to contact the researcher. Once contacted, the researcher will send an information sheet and full consent form to the participant for them to electronically sign and return. A time and date convenient for the participant will be scheduled for the interview to take place.

Measures, materials or equipment:

A semi-structured interview will be conducted online via Microsoft Teams. A copy of the interview schedule can be found in the appendices. A list of local and national resources for CHD and mental-health services will be provided as part of the debrief form (see attached) should anyone wish to receive further support. A computer will also be needed to conduct interviews and transcribe them.

Data collection:

Participants will be invited to take part in a one-to-one interview over the internet using Microsoft Teams software. They will be sent an informed consent sheet to read, sign and return to the researcher. Once completed, a link to the interview will be sent to the participant and the meeting will be hosted by the researcher in a private room. Participants can choose not to be video recorded if they wish, but the interview will be audio recorded using the record function on Microsoft Teams. Participants will be asked again verbally for their consent to take part in the study and a brief outline of topics will be presented.

Participants will be asked if they have any initial questions, and the researcher will then work through the interview schedule following up on any topics the participant wishes to discuss. Once the interview is completed (interviews are anticipated to last approximately 60-90 minutes), participants will be verbally given a debrief and sent a full debrief in writing via e-mail (see attached). Participants will be given the opportunity to check in with the researcher a week later in case they have anything else they wish to add. Participants can decline this offer if they wish. Should they have more they wish to share, a follow up interview will be scheduled to enable them to do so.

Data analysis:

Data will be analysed using Thematic Analysis (TA). This method has been chosen as TA enables the study of perceptions and experiences and is compatible with a critical realist position.

Confidentiality and security

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

Will participants data be gathered anonymously?

It will not be possible to collected data anonymously as the research is qualitative

If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)?

A pseudonym will be used on all transcripts of the interviews and once the thesis for which the research has been gathered has been examined, original recordings, initially saved on the UEL one drive, will be deleted (as they will contain images of the participants face). Any personal information collected (e.g. names, email addresses) will be stored securely on the UEL One Drive in a password protected file. Only the researcher and supervisor will have the password to this document and be able to access it. All personal data will be destroyed at the end of the project or at the point in which a participant has requested to withdraw from the study. Consent forms will also be stored in password protected files on the UEL One Drive and deleted once the projected is completed. Anonymised transcripts will be saved for two years after the project's completion date to enable publication and as part of quality assurance practise. Any published works will contain only excerpts from interviews given which will be reviewed to ensure no identifiable information is present. Data analysis and reporting will focus on broad themes from across all interviews.

How will you ensure participants details will be kept confidential?

Only the researcher and supervisor will have access to the full transcripts of all interviews. Any contact information for participants collected to organise interviews will be stored in an encrypted Microsoft word file and saved on the UEL One Drive separately to any transcripts of interviews. In the interview transcripts, any time the participants name is mentioned, it will be removed and replaced with a pseudonym name. Only excerpts of interviews will be included in any published works. These excerpts will be checked to ensure no identifiable information is present before publication.

How will the data be securely stored?

Transcripts will be securely stored on the UEL One Drive, with the Microsoft word files being encrypted with a password known only to the researcher and supervisor. Any records of interviews will be stored on the One Drive until the thesis has been examined, at which point the recordings will be deleted. Transcripts will also be encrypted with a password. Codes will be written on the transcripts so that the researcher can identify which transcript belongs to which participant to enable the accurate reporting of data. The codes and the participant to whom they are attached, will be known by only the researcher, supervisor and participant (should they want to withdraw from the study at a later date). A document with the codes on will be stored on a One Drive in an encrypted word document until the completion of the study at which point they will be deleted.

Who will have access to the data?

Only the researcher and supervisor will have full access to the data. Any published work will contain excerpts of transcripts or discuss overarching themes found across all interviews.

How long will data be retained for?

In line with the Data Protection Act, transcripts will be stored for 2 years. All recordings of interviews will be deleted as soon as transcripts have been completed.

Informing participants

Please confirm that your information letter includes the following details:

Your research title: ☒

Your research question: ☒

The purpose of the research: ☒

The exact nature of their participation. This includes location, duration, and the tasks etc. involved: ☒

That participation is strictly voluntary: ☒

What are the potential risks to taking part: ☒

What are the potential advantages to taking part: ☒

Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked): ☒

Their right to withdraw data (usually within a three-week window from the time of their participation): ☒

How long their data will be retained for: ☒

How their information will be kept confidential: ☒

How their data will be securely stored: ☒

What will happen to the results/analysis: ☒

Your UEL contact details: ☒

The UEL contact details of your supervisor: ☒

Please also confirm whether:

Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature.

No

Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

No, please see above under section 4

Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it be worth?

No

Risk Assessment

Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

Minimal psychological distress may occur as participants will be asked how they have experienced what could have been a difficult time for some. The interviewer will use her clinical skills to ensure that the participant feels comfortable and contained and will suspend the interview should the participant get too distressed. Information on CHD support services and mental health services will be provided on the debrief form.

Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

No

Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?

British Heart Foundation Helpline
Telephone: 0300 330 3311
Email: hearthelpline@bhf.org.uk

The British Heart Foundation has been selected as they have a helpline to support anyone with a diagnosis of a heart condition (including CHD) with COVID-19 related issues or concerns. They are a specialist charity with expertise in the area of heart conditions and will be able to provide tailored, medically accurate advice on this issue.

Mind (Mental Health Charity)
Telephone: 0300 123 3393 (Monday to Friday, 9am to 6pm)
Website: www.mind.org.uk

Mind has been selected as they can offer advice on local and national mental health services and their website includes lists of helplines, tips for managing mental health day-to-day and information regarding people's legal rights (including discrimination at work)

Samaritans
Telephone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

The Samaritans has been included as they offer a free 24-hour helpline to those experiencing mental health crises who may need to talk to someone urgently.

Does the research take place outside the UEL campus? If so, where?

NA as study will be online

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is required for this research, please tick to confirm that this has been completed:

☐

Does the research take place outside the UK? If so, where?

NA

If so, in addition to the ‘general risk assessment form’, a ‘country-specific risk assessment form’ must be also completed (available in the Ethics folder in the Psychology Noticeboard), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a ‘country-specific risk assessment form’ *is* needed, please tick to confirm that this has been included:

However, pleas ☐ o note:

For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on ‘sign in’ and then ‘register here’ using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance.
For *on campus* students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).
For *distance learning* students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

Disclosure and Barring Service (DBS) certificates

Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?

NO

If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to confirm that you have included this: ☐

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead: ☐

Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have ☐

included this instead:

If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these: ☐

If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this ☐

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children click here.

Other permissions

Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

NO If yes, please note:

You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see further details here).
However, the school *strongly discourages* BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged). If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.
IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly

through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises?

NO

If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application?

NA

Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.

No

Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here to confirm that you have included this written permission as an appendix:

☐

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation,’ or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature): Claire Russ

Student's number: 1725741 Date: 20/09/20

As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.

APPENDIX D: Ethics Approval

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Irina Anderson

SUPERVISOR: Kenneth Gannon

STUDENT: Claire Russ

Course: Doctorate in Clinical Psychology

Title of proposed study: The experience of the COVID pandemic for people with Congenital Heart Disease (CHD) in the U.K

DECISION OPTIONS:

APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*
Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ UM (Please approve but with appropriate recommendations)

☒

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: *Irina Anderson*

Date: 13/10/20

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

APPENDIX E: Ethics Amendment Approval

UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

Complete the request form electronically and accurately.
Type your name in the ‘student’s signature’ section (page 2).
When submitting this request form, ensure that all necessary documents are attached (see below).
Using your UEL email address, email the completed request form along with associated documents to: Dr Tim Lomas at t.lomas@uel.ac.uk
Your request form will be returned to you via your UEL email address with reviewer’s response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
Recruitment and data collection are not to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
A copy of the approval of your initial ethics application.
Name of applicant: Claire Russ
Programme of study: Doctorate in Clinical Psychology
Title of research: The experience of the COVID pandemic for people with Congenital Heart Disease (CHD) in the U.K.
Name of supervisor: Kenneth Gannon

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
Addition of The Somerville Foundation helpline on to the debrief form	As requested by the charity they also provide specialist support for those with a diagnosis of CHD. Giving additional information for where participants can seek help seems sensible
The Somerville Foundation agreeing to send out an advert for the research project	In order to improve participation numbers, using a charity such as the Somerville Foundation who specialise in supporting those with CHD, means the project is more likely to meet the numbers required for a meaningful analysis of data.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	Z	

Student's signature (please type your name): Claire Russ

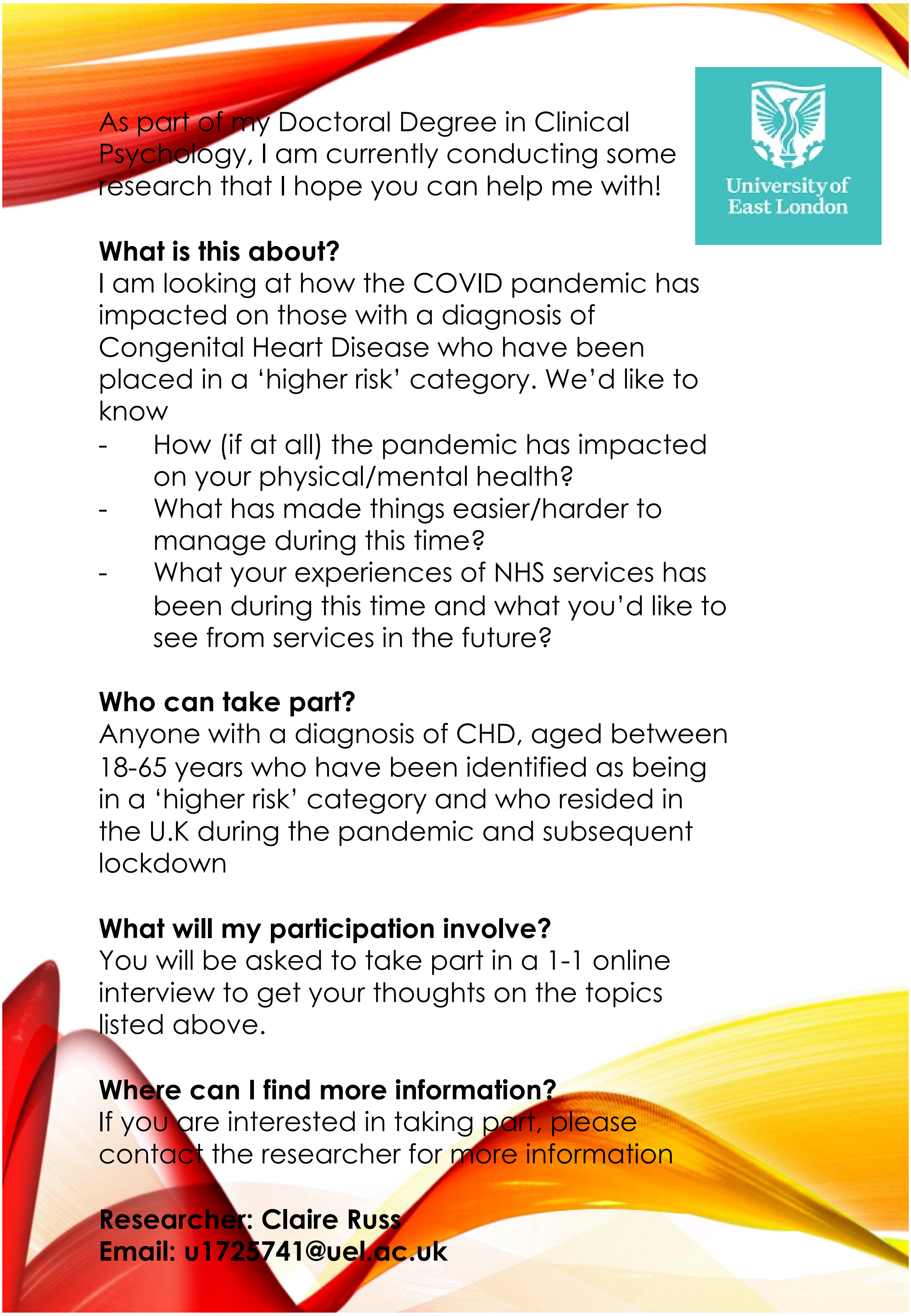
Date: 11.01.21

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Ian Tucker

Date: 18/01/21

APPENDIX F: Research Advert



As part of my Doctoral Degree in Clinical Psychology, I am currently conducting some research that I hope you can help me with!

What is this about?

I am looking at how the COVID pandemic has impacted on those with a diagnosis of Congenital Heart Disease who have been placed in a 'higher risk' category. We'd like to know

- How (if at all) the pandemic has impacted on your physical/mental health?
- What has made things easier/harder to manage during this time?
- What your experiences of NHS services has been during this time and what you'd like to see from services in the future?

Who can take part?

Anyone with a diagnosis of CHD, aged between 18-65 years who have been identified as being in a 'higher risk' category and who resided in the U.K during the pandemic and subsequent lockdown

What will my participation involve?

You will be asked to take part in a 1-1 online interview to get your thoughts on the topics listed above.

Where can I find more information?

If you are interested in taking part, please contact the researcher for more information

Researcher: Claire Russ
Email: u1725741@uel.ac.uk

APPENDIX G: Information sheet/Invitation letter

PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following
information carefully.

Research Title: The experience of the COVID pandemic for people with Congenital Heart Disease (CHD) in the U.K.

Who am I?

I am a postgraduate student in the School of Psychology at the University of East London and am studying for a Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?

I am conducting research into the experiences of the COVID pandemic, subsequent lockdown and continued safety measures for people with diagnosis of Congenital Heart Disease who have been placed in a ‘higher risk’ category. We are interested in knowing how the pandemic has impacted on those with a CHD diagnosis, whether your physical or mental health has been affected or not as a result of the pandemic and what factors have made things easier/harder to manage during this time. We are also interested to know what your experiences of NHS services have been like during this time and what you would like from them in the future. It is hoped that the information gathered will be used by NHS services to help meet the needs and challenges faced by those with CHD.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Why have you been asked to participate?

I am looking to involve anyone aged between 18- 65 years, with a diagnosis of Congenital Heart Disease who have been identified as being in a 'higher risk' category and who resided in the U.K during the pandemic and subsequent lockdown.

I emphasise that I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way and you will be treated with respect.

You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?

If you agree to participate you will be asked to take part in a one-to-one interview with me online using a software called Microsoft Teams. A link will be sent to you which will connect you to a video call. You can choose, by selecting options in the software to participate using audio only. The interview will last approximately 60 minutes and you will be asked about your experience of the pandemic, lockdown and current safety measures and how (if at all) it has impacted on your physical and/or mental health. The interview will be like having an informal chat and you are free to talk in as much detail as you wish or to decline to answer any questions. The interviews will be recorded so that they can be transcribed at a later date. Once the project has been completed, all recordings of the interview will be deleted.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of my research topic. Findings from this research will be shared with services so they have a better understanding of what their patients may want from them in the future.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times.

- Only myself and my supervisor will have access to video/audio files created and once the project has been completed, these will be deleted. Your name will not be included in the transcription of the interview
- You will not be identified by any written material (for example research publications) or in any write-up of the research
- You do not have to answer all of the questions asked and you can stop your participation at any time (if you wish, I would be happy to send you the list of planned questions beforehand)

What will happen to the information that you provide?

What I will do with the material you provide will involve

- All video/audio files will be stored securely on my Institutions OneDrive in a password protected folder, accessible only by myself and my supervisor. These will be deleted once the project has been completed.
- Transcriptions of interviews will be stored in encrypted, password protected files and saved on my Institution's OneDrive. You will be asked to provide a pseudonym which will appear on the transcripts and in any published work. Your name and e-mail address (required to participate in the study) will be stored in a separate password protected file and deleted once the project is complete.
- Once the data has been anonymised only myself, my supervisor and my course examiners will have access to the full transcriptions. Any work that is published may contain extracts from these transcriptions but they will be checked first to ensure no identifiable information is present. Publications will focus on broad findings from the research.
- Once the project is completed, the anonymised transcripts will be stored for 2 years in encrypted files after which it will be deleted

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated data, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible). If you choose to withdraw at this point, all files with your data in will be deleted.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Claire Russ
Email: u1725741@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Ken Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: K.N.Gannon@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk)

APPENDIX H: Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

The experience of the COVID pandemic for people with Congenital Heart Disease (CHD) in the U.K.

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Participant's Name (please note that typing your name will amount to a signature agreeing to your participation in the study):

Date:

APPENDIX I: Debrief form

University of East London

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on 'The experience of the COVID pandemic for people with Congenital Heart Disease (CHD) in the U.K.' This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

- Your personal contact details will be stored in an encrypted, password protected file on my Institution's OneDrive until the completion of the project, at which point this information will be deleted
- All video/audio files will be securely stored in a password protected folder on my Institution's OneDrive until the project is completed. At this point, recordings will be deleted. The transcriptions will not contain your name, and instead a pseudonym will be used.
- My supervisor and course examiners will have access to anonymised transcriptions but any published work in academic journals will contain extracts only (carefully selected to ensure no identifiable information is included) and will report on broad trends found across all interviews.
- Once the project has been completed, anonymised transcriptions will be stored for 2 years in case work is published.

- You have 3 weeks to withdraw your participation from this study after which it will no longer be possible to withdraw as data analysis will begin.

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

The Somerville Foundation Helpline
Telephone: 0300 015 1998

British Heart Foundation Helpline
Telephone: 0300 330 3311
Email: hearthelpline@bhf.org.uk

Mind (Mental Health Charity)
Telephone: 0300 123 3393 (Monday to Friday, 9am to 6pm)
Website: www.mind.org.uk

Samaritans
Telephone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

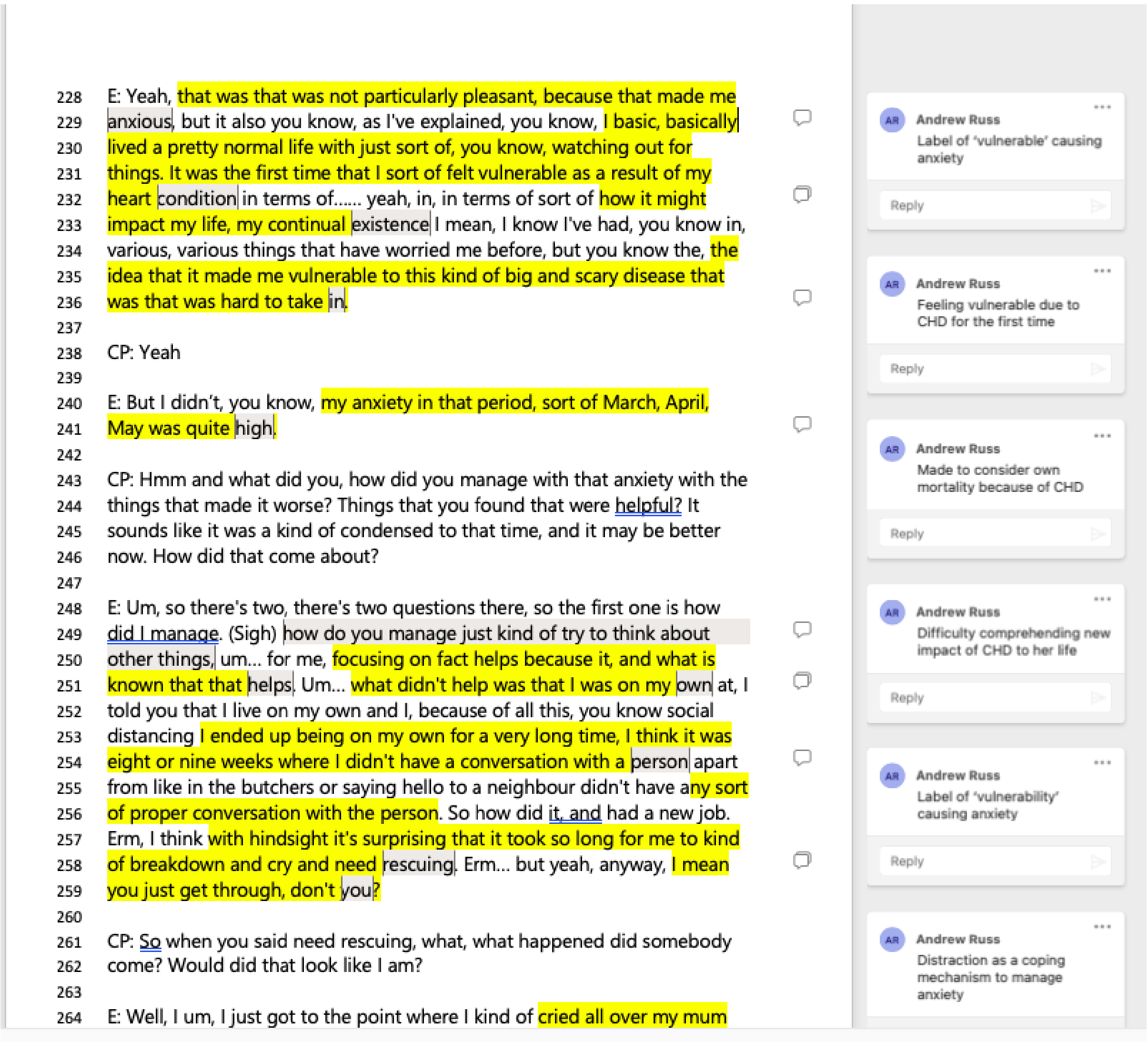
Claire Russ
Email: u1725741@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor Ken Gannon School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: K.N.Gannon@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: t.lomas@uel.ac.uk)

APPENDIX J: Annotated Transcript Extract



E: Yeah, that was that was not particularly pleasant, because that made me anxious, but it also you know, as I've explained, you know, I basic, basically lived a pretty normal life with just sort of, you know, watching out for things. It was the first time that I sort of felt vulnerable as a result of my heart condition in terms of...... yeah, in, in terms of sort of how it might impact my life, my continual existence I mean, I know I've had, you know in, various, various things that have worried me before, but you know the, the idea that it made me vulnerable to this kind of big and scary disease that was that was hard to take in.

CP: Yeah

E: But I didn't, you know, my anxiety in that period, sort of March, April, May was quite high.

CP: Hmm and what did you, how did you manage with that anxiety with the things that made it worse? Things that you found that were helpful? It sounds like it was a kind of condensed to that time, and it may be better now. How did that come about?

E: Um, so there's two, there's two questions there, so the first one is how did I manage. (Sigh) how do you manage just kind of try to think about other things, um... for me, focusing on fact helps because it, and what is known that that helps. Um... what didn't help was that I was on my own at, I told you that I live on my own and I, because of all this, you know social distancing I ended up being on my own for a very long time, I think it was eight or nine weeks where I didn't have a conversation with a person apart from like in the butchers or saying hello to a neighbour didn't have any sort of proper conversation with the person. So how did it, and had a new job. Erm, I think with hindsight it's surprising that it took so long for me to kind of breakdown and cry and need rescuing. Erm... but yeah, anyway, I mean you just get through, don't you?

CP: So when you said need rescuing, what, what happened did somebody come? Would did that look like I am?

E: Well, I um, I just got to the point where I kind of cried all over my mum

AR Andrew Russ
Label of 'vulnerable' causing anxiety

AR Andrew Russ
Feeling vulnerable due to CHD for the first time

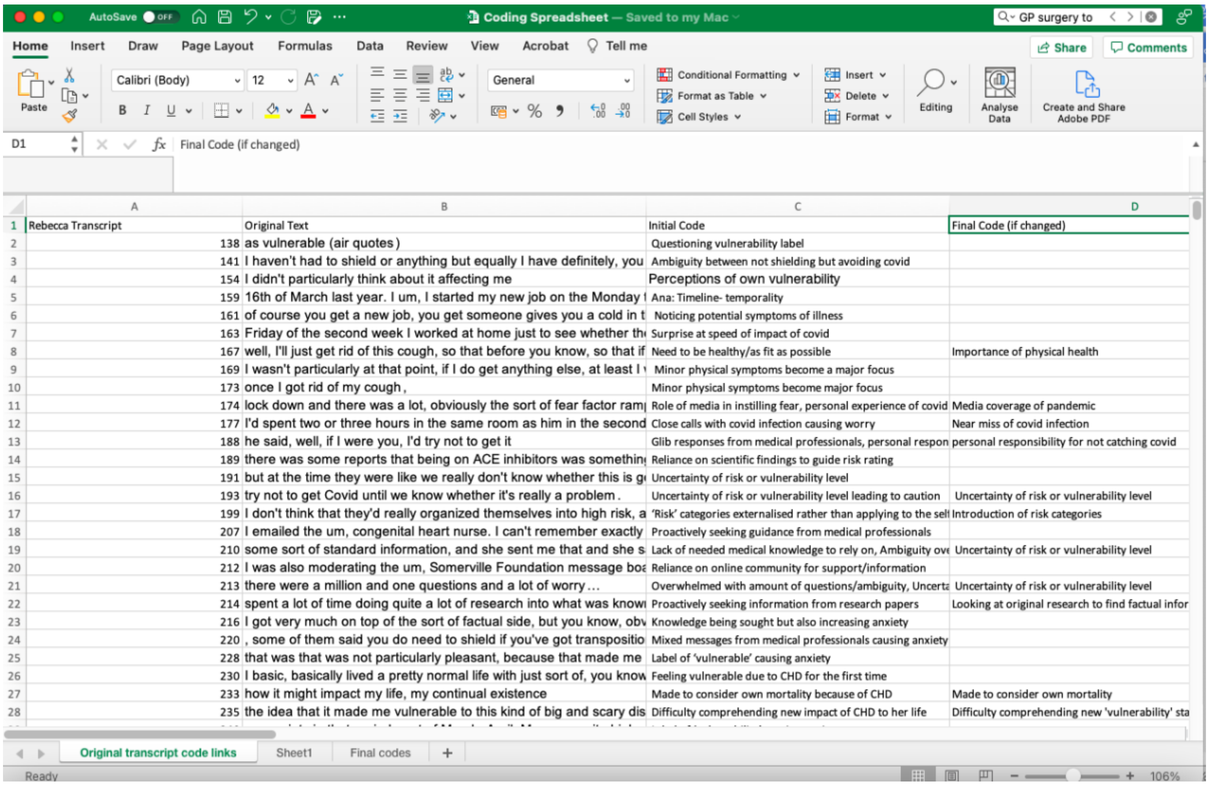
AR Andrew Russ
Made to consider own mortality because of CHD

AR Andrew Russ
Difficulty comprehending new impact of CHD to her life

AR Andrew Russ
Label of 'vulnerability' causing anxiety

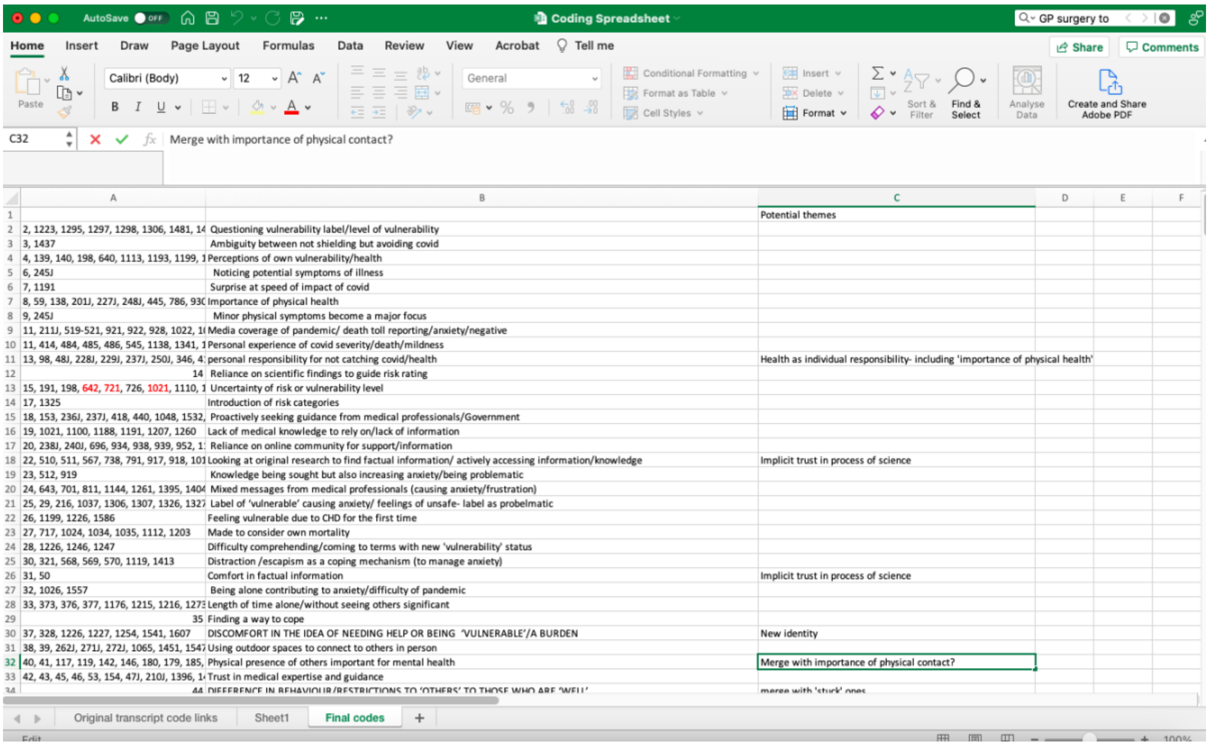
AR Andrew Russ
Distraction as a coping mechanism to manage anxiety

APPENDIX K: Excel spreadsheet of extracts and related codes



D1 Final Code (if changed)

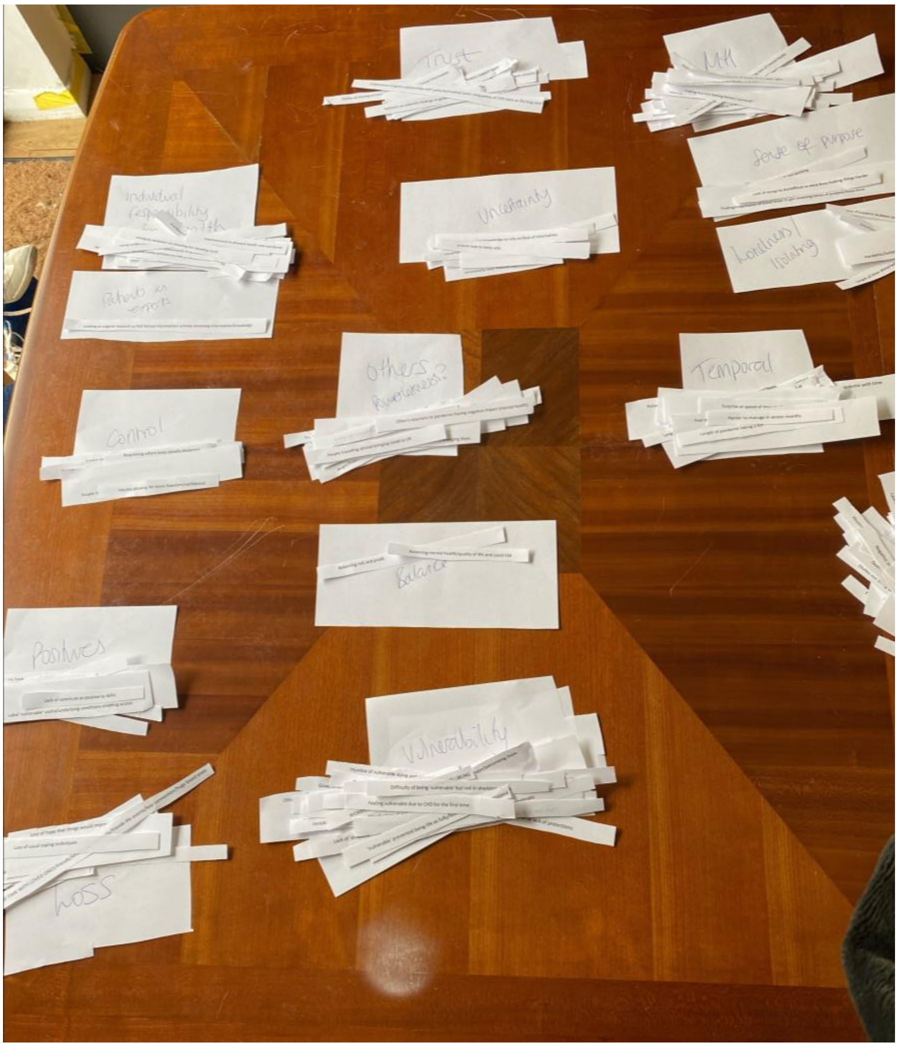
	A	B	C	D
1	Rebecca Transcript	Original Text	Initial Code	Final Code (if changed)
2	138	as vulnerable (air quotes)	Questioning vulnerability label	
3	141	I haven't had to shield or anything but equally I have definitely, you	Ambiguity between not shielding but avoiding covid	
4	154	I didn't particularly think about it affecting me	Perceptions of own vulnerability	
5	159	16th of March last year. I um, I started my new job on the Monday	Ana: Timeline- temporality	
6	161	of course you get a new job, you get someone gives you a cold in t	Noticing potential symptoms of illness	
7	163	Friday of the second week I worked at home just to see whether th	Surprise at speed of impact of covid	
8	167	well, I'll just get rid of this cough, so that before you know, so that if	Need to be healthy/as fit as possible	Importance of physical health
9	169	I wasn't particularly at that point, if I do get anything else, at least I	Minor physical symptoms become a major focus	
10	173	once I got rid of my cough ,	Minor physical symptoms become major focus	
11	174	lock down and there was a lot, obviously the sort of fear factor ram	Role of media in instilling fear, personal experience of covid	Media coverage of pandemic
12	177	I'd spent two or three hours in the same room as him in the second	Close calls with covid infection causing worry	Near miss of covid infection
13	188	he said, well, if I were you, I'd try not to get it	Glib responses from medical professionals, personal respon	personal responsibility for not catching covid
14	189	there was some reports that being on ACE inhibitors was somethin	Reliance on scientific findings to guide risk rating	
15	191	but at the time they were like we really don't know whether this is g	Uncertainty of risk or vulnerability level	
16	193	try not to get Covid until we know whether it's really a problem .	Uncertainty of risk or vulnerability level leading to caution	Uncertainty of risk or vulnerability level
17	199	I don't think that they'd really organized themselves into high risk, a	'Risk' categories externalised rather than applying to the sel	Introduction of risk categories
18	207	I emailed the um, congenital heart nurse. I can't remember exactly	Proactively seeking guidance from medical professionals	
19	210	some sort of standard information, and she sent me that and she s	Lack of needed medical knowledge to rely on, Ambiguity ove	Uncertainty of risk or vulnerability level
20	212	I was also moderating the um, Somerville Foundation message boa	Reliance on online community for support/information	
21	213	there were a million and one questions and a lot of worry …	Overwhelmed with amount of questions/ambiguity, Uncerta	Uncertainty of risk or vulnerability level
22	214	spent a lot of time doing quite a lot of research into what was know	Proactively seeking information from research papers	Looking at original research to find factual infor
23	216	I got very much on top of the sort of factual side, but you know, obv	Knowledge being sought but also increasing anxiety	
24	220	, some of them said you do need to shield if you've got transpositio	Mixed messages from medical professionals causing anxiety	
25	228	that was that was not particularly pleasant, because that made me	Label of 'vulnerable' causing anxiety	
26	230	I basic, basically lived a pretty normal life with just sort of, you know	Feeling vulnerable due to CHD for the first time	
27	233	how it might impact my life, my continual existence	Made to consider own mortality because of CHD	Made to consider own mortality
28	235	the idea that it made me vulnerable to this kind of big and scary dis	Difficulty comprehending new impact of CHD to her life	Difficulty comprehending new 'vulnerability' sta

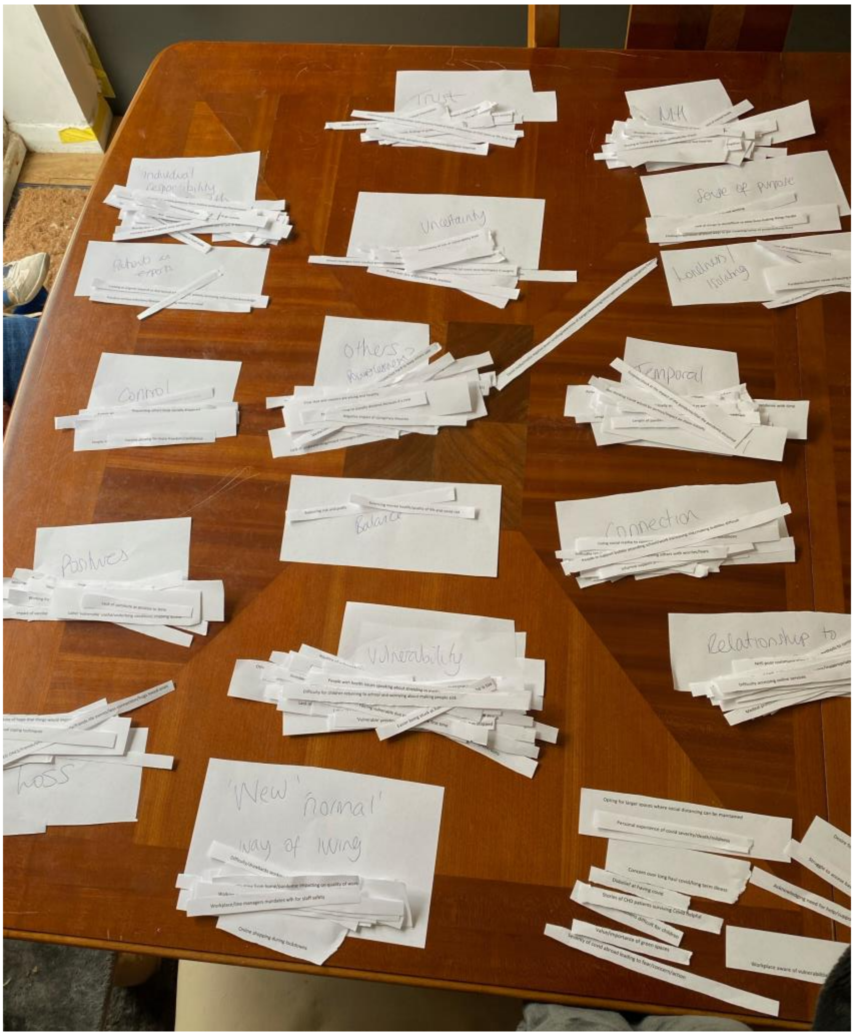


C32 Merge with importance of physical contact?

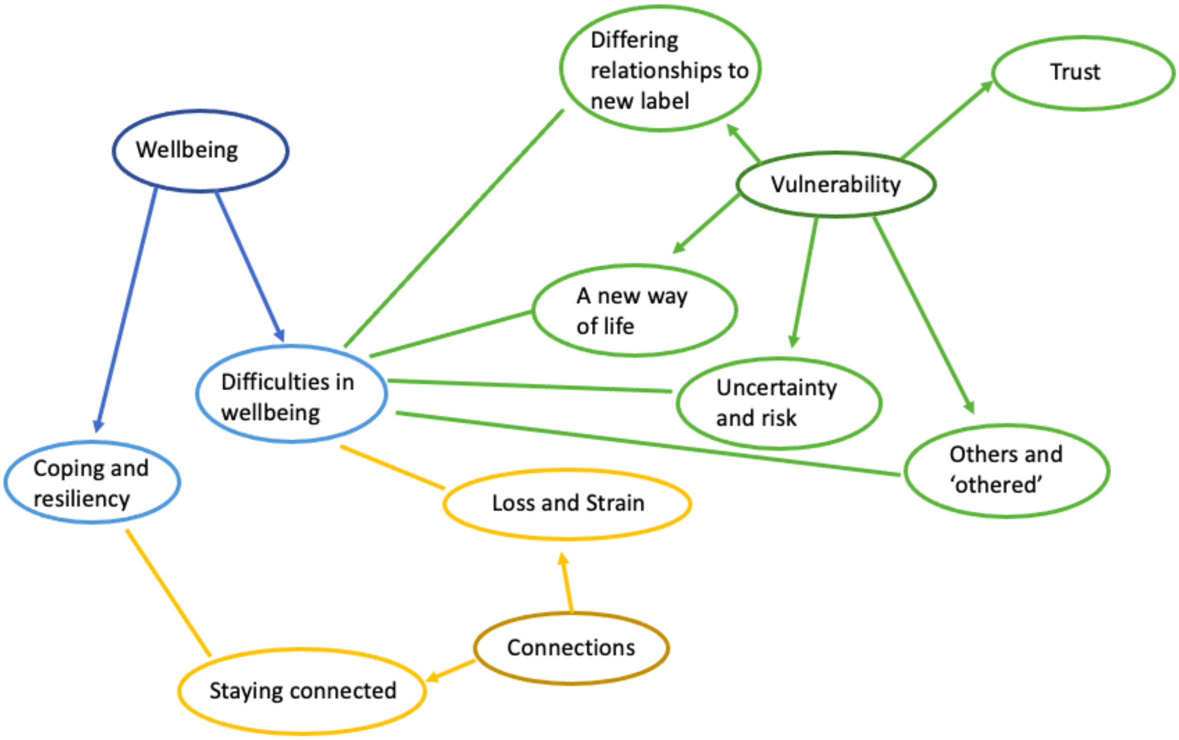
	A	B	C	D	E	F
1			Potential themes			
2	2, 1223, 1295, 1297, 1298, 1306, 1481, 14	Questioning vulnerability label/level of vulnerability				
3	3, 1437	Ambiguity between not shielding but avoiding covid				
4	4, 139, 140, 198, 640, 1113, 1193, 1199, 1	Perceptions of own vulnerability/health				
5	6, 245J	Noticing potential symptoms of illness				
6	7, 1191	Surprise at speed of impact of covid				
7	8, 59, 138, 201J, 227J, 248J, 445, 786, 93(	Importance of physical health				
8	9, 245J	Minor physical symptoms become a major focus				
9	11, 211J, 519-521, 921, 922, 928, 1022, 1(	Media coverage of pandemic/ death toll reporting/anxiety/negative				
10	11, 414, 484, 485, 486, 545, 1138, 1341, 1	Personal experience of covid severity/death/mildness				
11	13, 98, 48J, 228J, 229J, 237J, 250J, 346, 4	personal responsibility for not catching covid/health	Health as individual responsibility- including 'importance of physical health'			
12	14	Reliance on scientific findings to guide risk rating				
13	15, 191, 198, 642, 721, 726, 1021, 1110, 1	Uncertainty of risk or vulnerability level				
14	17, 1325	Introduction of risk categories				
15	18, 153, 236J, 237J, 418, 440, 1048, 1532,	Proactively seeking guidance from medical professionals/Government				
16	19, 1021, 1100, 1188, 1191, 1207, 1260	Lack of medical knowledge to rely on/lack of information				
17	20, 238J, 240J, 696, 934, 938, 939, 952, 1	Reliance on online community for support/information				
18	22, 510, 511, 567, 738, 791, 917, 918, 101	Looking at original research to find factual information/ actively accessing information/knowledge	Implicit trust in process of science			
19	23, 512, 919	Knowledge being sought but also increasing anxiety/being problematic				
20	24, 643, 701, 811, 1144, 1261, 1395, 1404	Mixed messages from medical professionals (causing anxiety/frustration)				
21	25, 29, 216, 1037, 1306, 1307, 1326, 1327	Label of 'vulnerable' causing anxiety/ feelings of unsafe- label as probelmatic				
22	26, 1199, 1226, 1586	Feeling vulnerable due to CHD for the first time				
23	27, 717, 1024, 1034, 1035, 1112, 1203	Made to consider own mortality				
24	28, 1226, 1246, 1247	Difficulty comprehending/coming to terms with new 'vulnerability' status				
25	30, 321, 568, 569, 570, 1119, 1413	Distraction /escapism as a coping mechanism (to manage anxiety)				
26	31, 50	Comfort in factual information	Implicit trust in process of science			
27	32, 1026, 1557	Being alone contributing to anxiety/difficulty of pandemic				
28	33, 373, 376, 377, 1176, 1215, 1216, 127	Length of time alone/without seeing others significant				
29	35	Finding a way to cope				
30	37, 328, 1226, 1227, 1254, 1541, 1607	DISCOMFORT IN THE IDEA OF NEEDING HELP OR BEING 'VULNERABLE'/A BURDEN	New identity			
31	38, 39, 262J, 271J, 272J, 1065, 1451, 1547	Using outdoor spaces to connect to others in person				
32	40, 41, 117, 119, 142, 146, 180, 179, 185,	Physical presence of others important for mental health	Merge with importance of physical contact?			
33	42, 43, 45, 46, 53, 154, 47J, 210J, 1396, 1	Trust in medical expertise and guidance				
34	44	DIFFERENCE IN BEHAVIOUR/RESTRICTIONS TO 'OTHERS' TO THOSE WHO ARE 'WELL'	merge with 'stuck' ones			

APPENDIX L: Photo of theme development




Trust
MH
Individual responsibility
Uncertainty
Sense of purpose
Return to experts
Loneliness/Isolating
Others awareness?
Temporal
Control
Balance
Connection
Positives
Vulnerability
Relationship to
Loss
'New' 'normal' way of living
Opting for larger spaces where social distancing can be maintained
Personal experience of covid severity/death/sickness
Concern over long haul covid/long term illness
Disbelief at having covid
Stories of CHD patients surviving Covid helpful
Value/importance of green spaces
Severity of covid abroad leading to fear/concern/action
Workplace aware of vulnerability
Difficulty accessing online services
Online shopping during lockdowns

APPENDIX M: Theme mapping



APPENDIX N: Field diary extract

Interview X

Feelings before

- Nervous as this was my first interview and I would be meeting a stranger. I was also worried about getting the technology to work

During Interview/ Process

- I noticed that whenever they spoke of what might be perceived as difficult issues, they often laughed and avoided talking about the emotion behind it. I was torn about pushing for more emotion and respecting where they were at in terms of what they felt able to talk about. I decided not to push but may have lost some key experiences
- Noted that the interview felt clunky in places initially where we switched from a topic onto a different area. Found that active listening and reflecting what the participant had said was a good way to both check in my understanding and also make these transitions onto another topic feel more natural.
- Participant mentioned difficulties dating and I was aware that I did not follow this up in as much detail as I might have done during the interview. I think I was unsure how to phrase follow up questions and didn't want to make the participant feel uncomfortable by asking about their sex life. My own anxiety around this topic prevented potentially useful information from being shared so I need to be mindful about following the participants lead more
- I was surprised at the end of the interview when I ask 'how was this process for you, talking about everything?' that they found it cathartic and really valued the space to talk about their experience. It highlighted to me how important these spaces are and made me reflect on how they can be difficult to come by outside of these sorts of situations or therapy

Reflections whilst transcribing

- I really noticed how difficult some of the participants experiences were and how poignant some of what they shared was. It made me think about the interview itself and I wondered if I was too absorbed in getting the information and keeping the interview going that I wasn't connecting properly with what was said. I will be mindful of this next time
- I noticed the participant justified the value of their life and their worthiness (when discussing the importance of locking down and people's reactions to it) in relation to her roles as an employee, a family member etc. I was struck that the participant felt the need to do this and the idea that their life didn't hold value simply because they were a person. It made me think about the values our society holds around the relative worth of certain groups and how unchallenged and ingrained these ideas are.
- Throughout the transcription I was aware that I thought the participant had explained themselves well and that there were lots of useful quotes that could be used. It made me think about 'good' participants and how these are often middle-class people who express themselves in a certain way and that this means other

voices are heard less. I need to be mindful of this in my analysis and try not to favour certain participant quotes over others.