

1 **Title:** “No official help is available” - experience of parents and children with congenital heart  
2 disease during COVID-19

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23

24 **Abstract**

25 **Purpose of the study**

26 The purpose was to explore the experience, information, support needs and decision-  
27 making of parents with congenital heart disease (CHD) during the COVID-19 crisis.

28 **Study design**

29 On-line survey design

30 **Setting**

31 An on-line survey with open/closed questions to explore the experiences of parents of  
32 children, as well as children and young people (CYP) with CHD during the COVID-19 crisis

33 **Patients**

34 Parents of children with CHD and CYP

35 **Results**

36 184 parents and 36 CYP completed the survey. Parents worry about the virus (86.4%) vs. CYP  
37 (69.4%), whilst (89%) parents are vigilant for symptoms of the virus vs. CYP(69.4%). A thematic  
38 analysis of the qualitative comments covered 34 subthemes, forming eight-overarching themes:  
39 Virus 1)risk of infection, 2)information, guidance and advice, 3)change in health care provision, and  
40 4)fears and anxieties; Lockdown and isolation 5)psychological and social impact, 6)keeping safe  
41 under lockdown, 7)provisions and dependence on others, 8)employment and income.

42 **Conclusions**

43 Parents and CYP were worried about the virus, although CYP less so. Parents and children  
44 however, were frustrated with the lack of specific and paediatric focused information and guidance,  
45 expressing disappointment with the adult centric information available. Parents also felt alone,  
46 especially with their concerns around the implications of cardiac service suspension and the  
47 implication for their child's health. In order to better support children and their families, resources  
48 need to be developed to address families' and CYP concerns for their health during this pandemic.

**What is already known?**

- People are feeling vulnerable and have heightened levels of stress during the COVID-19 pandemic
- Mental health and well-being of individuals has been adversely affected during this health crisis
- The COVID-19 pandemic has affected the mental health of parents due to uncertain financial circumstances, the closure of schools and suspension of educational services for children

**What this study adds?**

- Parents worry about the virus and are vigilant for symptoms of the virus or cardiac symptoms.
- Parents felt abandoned, unsupported by their Government, local and specialist CHD clinical team, and wanted information specific to their child's cardiac diagnosis
- Families feel forgotten and that medical/ surgical procedures children had been waiting for were no longer prioritized, which added another level of abandonment

## 52 **Background**

53           In December 2019 a novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)  
54 was identified (1), and the subsequent rapid transmission of infection around the world resulted in  
55 the World Health Organization (WHO) declaring the outbreak of SARS-CoV-2 disease (COVID-19) a  
56 pandemic in March 2020(2). Despite the high infection rate amongst adults, children appear to be  
57 remarkably unaffected by COVID-19 (1-5% of cases)(3, 4), as well as experiencing milder disease and  
58 significantly lower mortality rate (4). In the first three months of 2020 governments of the majority  
59 of European countries put measures in slow the rate of infection, using social distancing and  
60 lockdown measures, lasting until early summer.

61           Congenital heart disease (CHD) represents one third of all major congenital anomalies, with  
62 a reported UK prevalence of 9 per 1,000 live births(5) resulting in approximately 5,000 CHD births  
63 per annum, of which 725 require interventional cardiac catheterisation and 4,000 need surgery per  
64 annum(6). The recent health crisis has seen an unprecedented cessation of many Health Service  
65 outpatient clinics and all elective surgical procedures, including cardiac surgery suspended for three  
66 months from March 2020 (7). The hiatus of usual paediatric cardiology services during this crisis  
67 period may have caused significant parental anxiety as well as unintended consequences due to  
68 delayed intervention(8). The aim of this study was to explore experiences, information and support  
69 needs, and decision-making of parents of a child with CHD in response to the COVID-19.

## 70 **Methods**

71           A survey study of parents of children with CHD, children and young people (CYP); capturing  
72 experiences, decision-making, information and support needs during the COVID-19 crisis. The survey  
73 launched during the first infection wave of the COVID-19 pandemic within the UK and subsequent  
74 restriction of free movement under lockdown rules (opened 09/04/2020 and closed on 09/05/2020).  
75 The results in this study form part of a larger longitudinal study describing experiences of parents  
76 and children with various paediatric conditions. The study was approved by the University of

77 Southampton and NHS Health Research Authority Research Ethics Committees (Ethics Number IRAS  
78 nr. 282176)

### 79 **Study participants**

80 Parents of children and CYP with CHD were recruited through social media, national charities  
81 web pages and Facebook groups to minimise the burden on the health system during the COVID-19  
82 outbreak. Electronic consent was obtained through the online survey. The aim was to recruit  
83 sufficient numbers of participants to describe the variety of concerns and experiences within closed  
84 statements(9) as well as common themes from the descriptive analyses of the rich qualitative data.

### 85 **Survey**

86 The survey content is based on currently available literature(9, 10), expert health care  
87 professional input, and parents of children with CHD. Within the survey there a number of sections  
88 and number of closed statement items: Experiences(n=9), Information(n=4), Decisions(n=6) and  
89 Support needs(n=8). The closed statement items were on a Likert scale of Not at all(1), A little(2),  
90 Quite a bit(3), Very much(4). At the beginning of each section there was a free text box. The number  
91 of items was deliberately small, allowing for rapid analysis and dissemination. Feedback from  
92 parents (n=3) was sought about the survey in terms of content, language and inclusiveness of  
93 content, as well as the sensitivity around the timing of the research. Iterative changes were made  
94 accordingly.

### 95 **Data analysis**

96 Descriptive statistics were completed using IBM Statistical Package for Social Science (SPSS)  
97 (version 25, IBM, Armonk, NY, USA) summarising demographic data, and simple descriptive statistics  
98 of the closed statement. A thematic content analysis was used to explore responses to the open  
99 text boxes, informed by a three-stage coding process (11, 12): stage 1). An initial sample of 34  
100 comments were open coded into broad comment categories by two researchers (SS and RW), an  
101 initial framework was compiled, and conflict around themes was resolved with a third researcher  
102 (ASD); stage 2) the best-fit framework guided categorization of all comments from the data (LVM),

103 with further refinement (SS and RW); stage 3) overarching themes were identified. The number of  
104 comments was counted to identify the weight of themes. As there was considerable overlap in the  
105 rich data within the sections, the total number of comments did not match the number of  
106 participants.

## 107 **Results**

### 108 *Participants*

#### 109 *Parents*

110 184 people completed the survey, presented by 92%(n=169) mother, 9%(n=15)  
111 paternal/other. The median age of children was 8-years old (Interquartile range (IQR): 3, 13) and  
112 parents was 40(IQR: 33, 46). Children with CHD had a varying diagnosis with 16%(n=29) waiting for  
113 surgery and 84%(n=155) not waiting for any planned surgery. The geographic representation of  
114 respondents was well spread through the country with parents reporting from each of the four  
115 home nations of the UK (Table 1).

#### 116 *Children and young people*

117 36 children and young people (CYP) completed the survey. The median age of CYP  
118 completing the survey was 18 years old (IQR:17,22). Thirty children indicated their age 43% (n=13)  
119 were <=18 years old and 57% (n=17) were >=18 years of age. CYP with CHD had a varying diagnosis  
120 with 2.7%(n=1) waiting for surgery and 72.2%(n=26) not waiting for any planned surgery (Table 1).

## 121 **Closed item statements**

### 122 *Parent*

123 Many parents worry about the virus (86.4%), and potential symptoms (89%), in addition to  
124 considerable concern regarding the ability of their child's heart to cope if cardiac symptoms were  
125 triggered by the virus (88%). Respondents felt they did not receive adequate/sufficient information  
126 from their child's clinical team (85%), and wanted information specific to their child's cardiac  
127 diagnosis (82%). Over half of parents felt their child should be isolated from everyone except parents  
128 (54%) and worried about health care professionals (HCPs) coming into the home (70%). Parents

129 were worried they might catch the virus (63%) and if so, their child would catch it from them (85%).  
130 All parents accessed information on social media (100%), which for some (48%) led to anxiety.  
131 Three-quarters of respondents worried hospitals were no longer a safe place (77%).Planned  
132 appointments or surgery (84%) were rescheduled in consultation with the medical team, with a  
133 proportion of parents (16%) making the decision not to attend without consulting their team (Figure  
134 1). Parents would welcome support to reduce their own worries relating to the virus (36%) and help  
135 to support their children (28%).

### 136 *Children and young people*

137 Worries of CYP mirrored that of parents, although to a lesser extent. CYP worry about the  
138 virus (69.4%), and are vigilant for symptoms of the virus (69%). The majority of respondents worried  
139 that hospitals were no longer a safe place (69%). Respondents felt they did not receive information  
140 they needed from their clinical team (64%), and would have wanted information specific to their  
141 cardiac diagnosis (64%).

### 142 **Open text boxes**

143 From the 184 parent respondents (n=141) provided comments, and from the 36 CYP  
144 respondents (n=25) comments. Overall, the responses covered 34 subthemes, forming eight  
145 overarching themes, related to the virus (four themes) and lockdown/shielding or isolation (four  
146 themes): *Virus*: 1)information, guidance and advice 2)change in health care provision, 2)risk of  
147 infection, and 4)fears and anxieties; *Lockdown and isolation*: 5)psychological and social impact,  
148 6)keeping safe during lockdown, 7)provisions and dependence on others, 8)employment and income  
149 (Figure 2;Table 2).

### 150 ***Virus***

#### 151 *Parents*

152 Most comments concerned the virus (n=56), with almost two-thirds of respondents (n=83)  
153 describing concerns about their child's risk to their heart and ability to cope or overcome infection  
154 with the virus, how their heart or lungs would cope (n=18). Some parents (n=10) were worried about

155 elective surgical procedures being delayed, and the negative consequences for their child. Many  
156 parents reported feeling abandoned by the specialist clinical team or the Government or HCPs in  
157 general (n=34).

158 Parents reported that information provided them was either non-existent or inconsistent  
159 within the home nations (n=21) they were also upset about the lack of support regarding the virus  
160 from their local team, specialist clinical team or The Government. Parents were frustrated the  
161 information provided related to adults. Parents wanted specific information relating to COVID-19  
162 and their child's particular heart defect, as well as what to do if they or their child contracted COVID-  
163 19. They as wanted reassurance they were not alone, and wanted letters to be able to stay home  
164 with their children (n=66).

#### 165 *Children and young people*

166 Most comments from CYP described a fear of contracting the virus and not recovering (n=16),  
167 although some had no concerns (n=4). CYP wanted more information specific to their cardiac diagnosis  
168 (n=6) and almost half of them (n=12) had not left home since lockdown began. CYP would have liked  
169 more support with information specific to their cardiac diagnosis(n=7).

#### 170 ***Lockdown and isolation***

##### 171 *Parents*

172 Parents described the psychological impact of the emergence of the virus and subsequent  
173 lockdown (n=13), for both themselves and their children. Parents also raised concerns about keeping  
174 their child safe during lockdown, and how restrictions would be lifted to ensure safe re-integration.  
175 Accessibility of grocery deliveries and food supplies were a concern for parents(n=11). A small  
176 number of parents raised financial or employment worries(n=3), with some parents who worked on  
177 the frontline or were keyworkers lived separately to keep their family safe.

##### 178 *Children and young people*

179 CYP reported feeling sad, panicked, isolated and missing their friends (n=12). The same  
180 number of children also reported feeling sad and bored.



181 **Information**

182 *Parents*

183 Parents reported accessing most information from British Heart Foundation (n=15), other  
184 CHD charities (n=23) British Congenital Cardiac Association (n=9), in addition to news outlets (n=54),  
185 NHS/ Government website (n=44), hospitals (n=19), World Health Organisation (n=10) and social  
186 media (n=24).

187 *Children and young people*

188 Information sources were parents (n=8), news sites (n=16), although children reported  
189 worry and concern about conflicting/ untrustworthy information (n=6).

190 **Support**

191 *Parents*

192 Parents wanted more support getting letters to gain delivery slots and what to do when  
193 lockdown restrictions are lifted (n=18).

194 *Children and young people*

195 CYP would have liked more support with mental health and well-being (n=4) and support with  
196 school or decisions around college.

197 **Decisions**

198 *Parents*

199 The majority of parents (n=92) did not rely on official advice regarding clinical vulnerability  
200 and took the decision to keep their child at home 'shielded' based on 'gut instincts' and relying on  
201 their own judgment.

202 *Children and young people*

203 The majority of CYP described trying to keep safe by staying indoors, sanitizing hands and  
204 the family home (n=16). A number of children (n=4) were grateful for the study being conducted, as  
205 they felt they were often forgotten or overlooked.

206 **Discussion**

207 To our knowledge this is the first study to report the experiences of parents of children and  
208 experiences of CYP with CHD during the COVID-19 crisis. The majority of parents expressed an  
209 overwhelming sense of worry about the effects of the virus, and the potential impact this may have  
210 on their child's heart should they contract the illness. This worry also resonated amongst CYP,  
211 although fewer were as concerned about the virus and some children were able to rationalize that  
212 adolescents did not appear to be much affected by the virus.

213 The majority of parents surveyed electively withdrew themselves and their children with  
214 CHD and other family members from society before or immediately as government lockdown was  
215 initiated. Reasons for this were fear of the unknown effects arising from a lack of specific  
216 information, and distrust in the adult-centric advice given. This was similarly echoed by CYP who  
217 wanted paediatric-specific information. Some of the children and CYP included in this survey had  
218 unrepaired or palliated CHD, but many had haemodynamically inconsequential lesions, and it is  
219 striking that even these families experienced uncertainty and anxiety related to their CHD-associated  
220 risks.

221 Although clinical teams provided support to parents and CYP with CHD, providing available  
222 information during the COVID-19 crisis, this is not how it was perceived by parents, particularly with  
223 respect to letters to support them being able to stay at home with their children. Further to this,  
224 parents felt abandoned and alone, especially with their concerns around the implications of cardiac  
225 service suspension and the implication for their child's health. Concerns regarding perceived  
226 vulnerability of their children may have been further exacerbated following reports of COVID-19 or  
227 COVID-19 like symptoms with hyperinflammatory multisystem syndrome temporally associated with  
228 COVID-19 (PIMS-TS) and atypical Kawasaki disease(13), as such it may be an important lesson for us  
229 as a health care community to recognize the potential psychological impact media reports may have  
230 on parents of children with CHD(14), and their increased vulnerability as a result.

231 CYP reported feeling panicked, isolated and missing their friends, as well as feeling sad and  
232 bored. There are profound consequences for the mental-health and well-being of children as a result

233 of social distance strategies to contain the spread of the virus(15); in addition there may be long-  
234 lasting consequence of educational poverty and ‘diminution of educational opportunities’ arising  
235 from school-closures(16, 17), which may more adversely affect children with serious conditions. This  
236 pandemic has raised many societal issues relating to how children are treated and viewed during a  
237 pandemic(17), and the interests of children, particularly those with complex health and social needs,  
238 should be at the heart of any recovery plan to get back to normal or ‘new normal’. Larcher *et al*(17),  
239 raised an important question , ‘*how society views children; should they be regarded as pawns,*  
240 *pathfinders or partners in this enterprise*’. We assert that this process starts with providing children  
241 with specific information relating to the effects of COVID-19 on children as a whole, as well as in the  
242 context of those with serious conditions. Our survey suggests parents of children with CHD, as well  
243 as CYP feel scared, abandoned and frustrated at the lack of bespoke information that talks to them  
244 about them during the COVID-19 crisis.

245         The limitations of this work include the small sample size and potential exclusion of  
246 individuals with digital poverty, literacy and language issues. Although charities and support groups  
247 of children with CHD were targeted, some groups might have been overlooked thus imposing  
248 sample bias. The survey also represents a maternal view-point as the majority of respondents in the  
249 adult survey were women.

250         Despite these limitations we believe the findings of this survey are important requiring a  
251 national conversation as to how parents and their children with CHD are better supported in the  
252 future, particularly if further periods of social distancing measures are required which result in  
253 closure of schools. Larcher *et al*(17) propose that article 12 of the United Nations Convention on the  
254 Rights of the Child(18) should be invoked requiring, ‘*children to be informed and consulted over*  
255 *matters that concern them and that their views be given due weight in accordance with their age*  
256 *and maturity*’ and is in keeping with the NHS ethos of ‘*no decision about me, without me*’. For the  
257 future, it is imperative we ensure better support and information for families to reduce the effects  
258 of social isolation, medical and educational deprivation.

259 **Conclusion**

260 Parents were around the effects of the virus, as were CYP although to a lesser extent.  
261 Parents felt unsupported, abandoned and frustrated with the lack of specific and focused  
262 information and guidance, expressing disappointment with the adult centric information. In order to  
263 better support children and their families, developed resources need to address families' concerns  
264 for their children's health during this pandemic.

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271

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273 None

274

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277

278 **CONTRIBUTORS STATEMENT:**

279 Authors made the following contribution to the manuscript: (1) Anne-Sophie Darling formulated the  
280 original idea and wrote the study design including the survey, (2) Luise Marino, Richard Wagland,  
281 Sam Sodergren, Anne-Sophie Darlington, David Culliard analysed the data, (3) Luise Marino drafted  
282 the manuscript, (4) Tara Bharucha, Richard Wagland, Sam Sodergren, Anne-Sophie Darlington  
283 contributed to revising the manuscript for important intellectual content, (4) and all authors  
284 provided final approval of the version to be submitted.

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**Table 1: Diagnosis**

<b>Respondents – region</b>	<b>% (n=184)</b>
United Kingdom	3.8% (7)
Northern Ireland	20.1% (37)
Scotland	5.9% (11)
Wales	7.0% (13)
United Kingdom	7.0% (13)
Southern England	36.4% (67)
Northern England	19.5% (36)
<b>Parent reported diagnosis</b>	<b>% (n=184)</b>
ASD, VSD or AVSD	13.0% (24)
Pulmonary stenosis	5.4% (10)
TOF or DORV	17.4% (32)
Left heart obstruction	14.7% (27)
Transposition of the great arteries	11.4% (21)
Univentricular heart physiology	26.1% (48)
Ebstein's anomaly	0.5% (1)
Other complex CHD	8.2% (15)
Cardiomyopathy or cardiac transplant	2.2% (4)
Complete heart block	1.6% (3)
Long QT syndrome	1.1% (2)
<b>CYP reported diagnosis</b>	<b>% (n=36)</b>
Waiting for surgery	2.7% (n=1)
No surgery planned	80.5% (n=29)
Don't know	16.7% (n=6)
VSD	11.1% (4)
Pulmonary stenosis	2.7% (1)
TOF	2.7% (1)
Left heart obstruction	11.1% (4)
Transposition of the great arteries	16.6% (6)
Univentricular heart physiology	13.8% (5)
Ebstein's anomaly	2.7% (1)
Congenital heart disease/ don't know	50% (13)

ASD: atrial septal defect; AVSD: atrioventricular septal defect, CHD: congenital heart disease; CYP: children and young people; DORV: double outlet right ventricle; TOF: tetralogy of Fallot; VSD: ventricular septal defect



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**Table 2 CHD: Experiences of Covid-19: Table of themes from 141 comments from a total of 184 parent respondents (76.6% of total respondents) and 24 comments from 36 CYP (66.6%)**

Theme	Subtheme	Number	Illustrative comments parents	Number	Illustrative comments CYP
<b>VIRUS</b>					
<b>1) Risk of infection</b>	Concern over child's low immunity	41	We are conscious if he is to catch it then as his immune system is poorer than his brother it would make it harder for him to cope with, we have made sure we are stocked up with paracetamol and his inhalers if required.	16	I also am concerned if I get the virus and get frustrated that it is not obvious that I am high risk to strangers so they don't distance themselves from me if I go for a walk
	Concern over visiting hospitals	9	Her appointments are cancelled. I worry about taking her to hospital. I feel the lock down has severely let down kids with special needs.	3	I am also worried about appointments at the hospital and whether I'll be able to have my normal checkups to see how my progress is doing
	Decision to remove child from school prior to lockdown	10	We have self-isolated since the week before lockdown, we also brought our older children out of school 3 days before the official school closure.	12	I have been in isolation for 41 days now. My parents took me out of school a week before they officially shut for protection.
	Family member has / had Covid-19	5	Even though we have not been confirmed as having the virus at the end of February 3 out of 4 of us as a family experienced symptoms that we believe could have been Coronavirus.	3	I definitely think that both my dad & I, have had it, however if my dad would've gotten tested, I would feel more at ease.
	Concern over infection entering the home from parent having to work or shop for provisions	25	Massive concerns as never received a letter for shielding. I'm a nurse and frontline and my husband is also a key worker.	5	I am currently self isolation away from home as my mum is a key worker. I initially self isolated at my Grandma's house, and she did the shopping for us. However she then became symptomatic. I had to leave my Grandma's and find somewhere else to stay. I could not return to my accommodation in Sheffield as I had no way of getting food/other essentials. I could not go to either of my parents' houses as they are both key workers. I am staying in a friend of a friend's

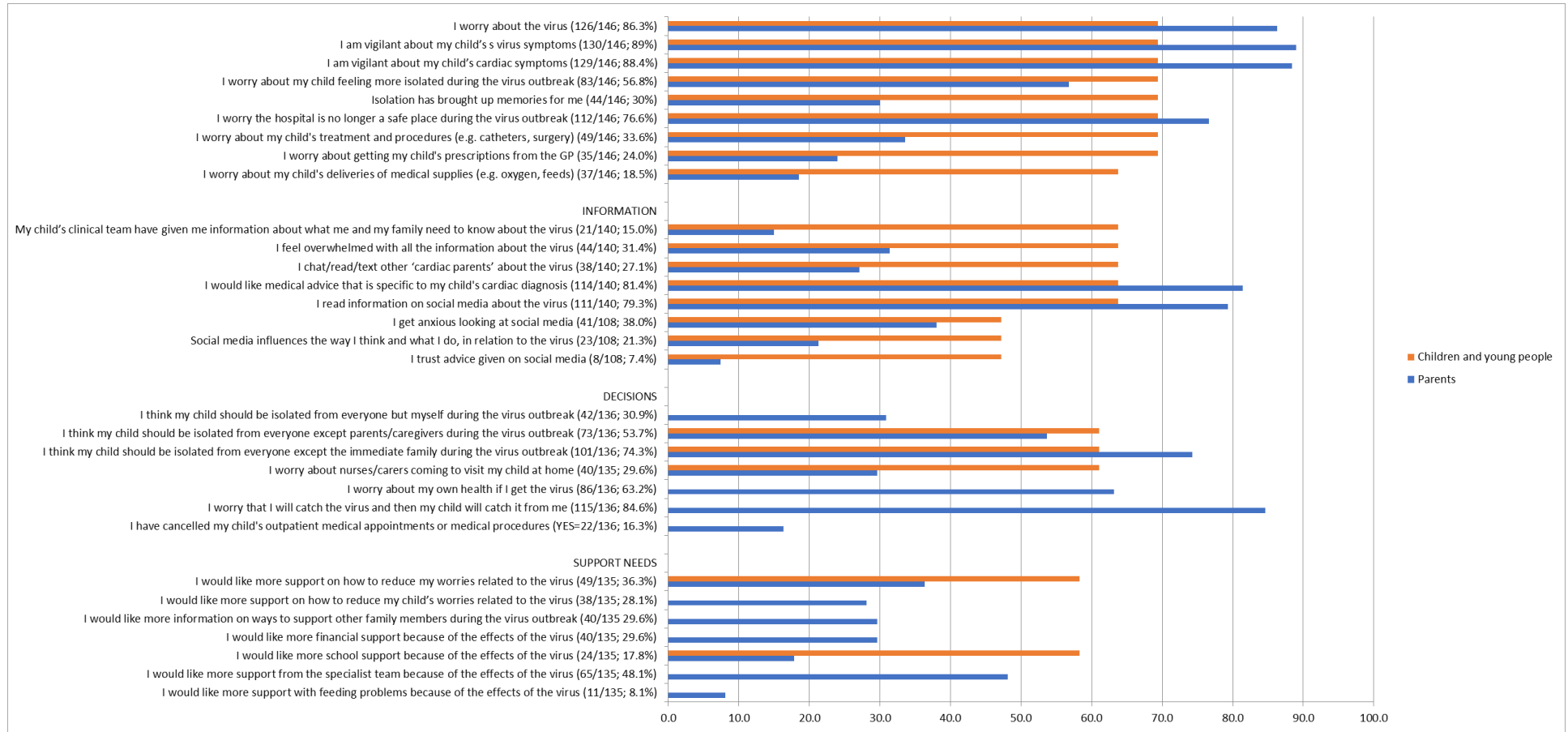
					stanger's house for the next 12 (possibly longer) weeks.
	Vigilance of symptoms of virus infection	1	Lucky enough we haven't experienced any signs or symptoms of the virus we just worry everyday.	3	I know that I'm at a higher risk than others and it's very worrying.
<b>2) Information, guidance and advice</b>	Limited information/ mixed messaging	56	When I contacted my GP or cardiac team to see how this could potentially affect him they just referred me back and forwards to each other or to the NHS website.	12	No more information the world is filled with differing information.
	Need for targeted advice and support	9	Information on how children with significant cardiac conditions (e.g. single ventricle) who have had the virus have coped and any specific advice on what to do if my cardiac child gets the virus, including ability to get tested to confirm Covid 19 in my cardiac child.	6	There isn't very much information for those that suffer from non- chronic conditions and the risk factor. Even at first the matter of self isolation was not expressed by the Government with enough clarity or soon enough.
	Information regarding child's vulnerability status not issued	22	Had no letter from GP or doctor. All advice we have found we looked for on charity websites. Able to get the information from British Congenital Cardiac Association and following their guidance. Mostly lost as to whether classed as vulnerable or extremely.	3	It's worrying but everyone seems to keep emphasizing the fact that the virus poses a much smaller threat to adolescents.
	Feel need to seek info from other sources	5	The BCCA produced a guideline on CHD and the Coronavirus which was very helpful. Government advice in regards to this has been limited. It is a very worrying time for everyone and difficult to know what is best especially when restrictions are lifted and it will be down to parents make the decision on returning to school etc. and when.	16	Medical bodies have contrasting information- I feel safer switching off.

<b>3) Healthcare provision</b>	Concern over sub-optimal treatment and care might be missed	32	She was due to have surgery at the start of April but this has been cancelled and have not heard anything about it being rescheduled anymore soon. Her sats are currently 74% so this worries me.	2	3 weeks ago, I was supposed to get an heart monitor implant in Leeds, however it was cancelled. I was looking forward to getting the monitor because my heart palpitations have been getting worse, where I can feel my heart stopping then restarting. I was gutted, I had waited so long for the appointment.
	Lack of contact from cardiac team	31	I haven't heard anything from my daughters gp or her cardiac consultant.	2	And its selfish to ask to get more info from my cardiologist/ hospital as they are now taking care of all the COVID19 patient
	More support required	11	He has had his biweekly saturation checks cancelled and has not had any contact with the community nurses for three weeks.	4	More social support to stop me feeling lonely with my heart condition. It's something none of my friends can relate to so it's hard explaining my worries about it to them
	New ways of working in the hospital	2	To face nurses gowned and masked, which terrified her.	1	More communication from my consultant team advising me on what to do.
	Hospital facilities strained	3	I feared that if he caught any virus and needed hospitalisation (as has happened previously) then they would be overstretched.	2	I am also worried about appointments at the hospital and whether I'll be able to have my normal check-ups to see how my progress is doing
<b>4) Fears and anxieties</b>	General expressions of fear	8	She talks about dying alone if she catches the virus, and her sleep pattern is totally fractured. If she does sleep, she has nightmares about it all.	3	There have been moments when I've been scared, like when I heard about the death of a 13-year-old with no underlying health issues, but thankfully my family have been very good at staying cautious when going out so I'm hopeful I'll make it through.
	Concern over ability to look after child if parent ill or dies	2	Concerned that if family members become unwell who will be able to take care of children.		
	Concern child or parent will die	18	Scared that she would be seriously ill or die if she contracted it	1	Family members have passed away from the virus and parents are key workers meaning huge concern for the worry of passing on the virus to me. Used to go to the gym almost everyday and now scared to exercise through seeing how if healthy people are dying the risk is even worse for me

	Things could be worse	4	Great experience with my son, having been contacted and arranged surgery to close his VSD within a week.	4	Stay inside dont be stupid
	Separation if child becomes ill from rest of family	1	If he DOES get ill, I would like to know if I'm going to be allowed to come into hospital with him - he's 16, an "adult" according to NHS regs, but we're still "in transition" and he's not a very mature 16, and still very needy.	5	Very worried about what impact it would have on me and my family if any us of were to get covid 19.
	Child has had/possibly had Covid-19	5	I believe she had the virus mid to end of March, 111 were no help with no specific guidelines, just told to self-isolate, felt very alone and scared.	3	About 2 weeks ago, I went to my local a&e hospital due to swelling on my abdomen and chest pain, all was fine, but about 4 days later I started showing symptoms for the coronavirus. I couldn't get out of bed as I was too dizzy, I was breathless just sitting down and I slept for about 2 days then it suddenly disappeared.
<b>5) Psychological and social impact</b>	Psychological impact on child and family, missing out on life, boredom	32	My son is struggling as he doesn't really cope with change. He finds it too much. He is missing nursery. Nursery was helping with his speech	4	Constantly sanitising the house and hands as this virus has brought my OCD syptoms back meaning I constantly feel germy. Change clothes the seconed I come in the house from essential shopping if I can't get someone to do it for me
	Parental coping (struggles, strategies used)	25	The situation is heartbreaking in what should be the happiest time of their lives.	3	However I believe my mum is going to extremes measure by wiping down shopping and leaving shopping out of my touch for at least 3 days she uses gloves to touch them as she believes it can still live on surfaces such as metal (tin) for a week.
	Missing family and friends	4	My daughter has been confused, worried and lonely. She misses her friends and family. She's an only child, and become very clingy.	12	Feel fed up, bored, Sad that I can't go out. Missing not seeing people. Sometimes upset
	Impractical nature of social distancing	4	I am concerned about how we will get our CHD child safely back into school if we don't know who has	5	What is more 'annoying' is other people telling me to be extra careful. I know I have to be careful - I've left the house only 3 times in the

			had it and whether there is immunity in the general population. Is there any advice about returning to socialising with others?		past 5 weeks, and it just adds extra pressure: makes you feel like you are ill and need looking after.
	Social and educational development	8	Impact to the child who also has autism of length of time away from school	3	I would like to know what's going to happen in September as I'm starting an access course, however I know that no one really knows what's going on. Therefore I'm just going to have to wait for some more information.
	Missing emotional support for parents from friends and family	1	Concern over balancing social distancing and maintaining positivity with a 18 year old who have all their plans put on hold and life changed dramatically.	12	What is more 'annoying' is other people telling me to be extra careful. I know I have to be careful - I've left the house only 3 times in the past 5 weeks, and it just adds extra pressure: makes you feel like you are ill and need looking after.
	Separation from partners/parents/children	2	My husband is a paramedic so he has moved out so that he can continue to work and we can stay safe.	3	I am currently self-isolation away from home as my mum is a key worker. I initially self-isolated at my Grandma's house, and she did the shopping for us. However she then became symptomatic. I had to leave my Grandma's and find somewhere else to stay. I could not return to my accommodation in Sheffield as I had no way of getting food/other essentials. I could not go to either of my parents' houses as they are both key workers. I am staying in a friend of a friend's stangers' house for the next 12 (possibly longer) weeks. I feel so lonely.
<b>6) Keeping safe under lockdown</b>	Concern over societal compliance in social distancing in society and delayed lockdown	12	I am currently living with my partners family who are not obeying the social distancing rules and that has led to major anxiety and distress.	6	I find that places with lots of people - even if they are spread thin - are a particular cause of anxiety for me.
	Being on lockdown keeps child safe	4	To begin with it terrified me. I was having to go into work as I am a key worker, however once we got the	6	I've found that while staying at home, I don't often think about the virus and I feel as though it's a problem that's far removed from me.

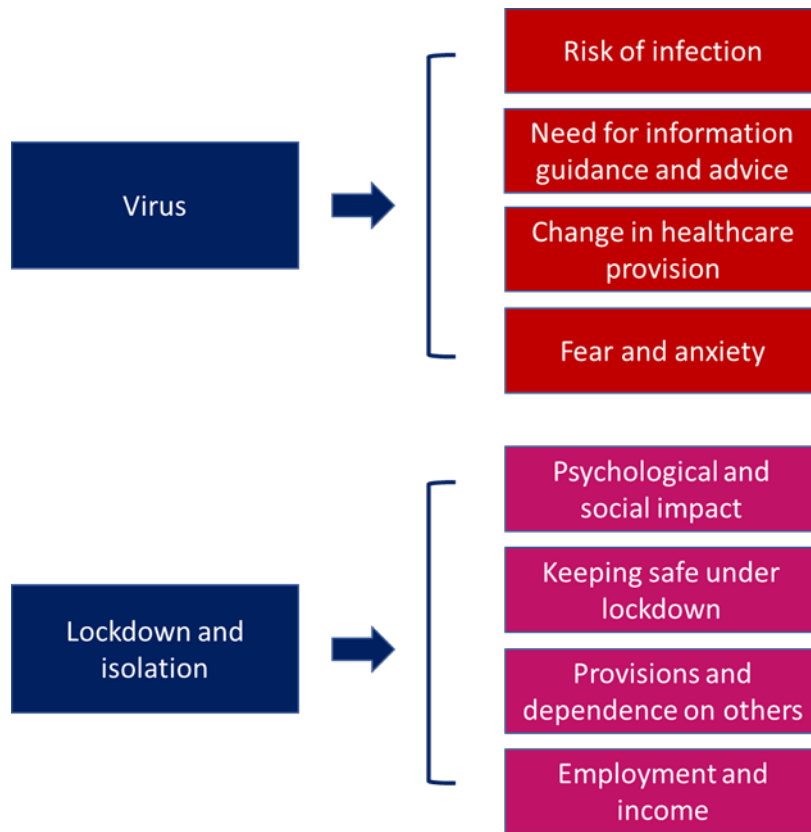
			letter from the welsh government I was given special leave from work to keep our son as safe as possible. This was a huge relief.		
	Concern once restrictions are lifted/ adjustment concerns	7	It is a very worrying time for everyone and difficult to know what is best especially when restrictions are lifted and it will be down to parents make the decision on returning to school etc. and when.	4	I would like to know what's going to happen in September as I'm starting an access course, however I know that no one really knows what's going on. Therefore I'm just going to have to wait for some more information.
<b>7) Provisions and dependence</b>	Difficulty securing provisions (food, cleaning, medication)	14	Struggling to get food. Have priority slots with Tesco shopping but no slots available	1	I am now on the vulnerable list, so getting access to food deliveries is great.
	Lack of priority status	5	Our GP doesn't what to advise, public health England say stay indoors but won't give a letter of vulnerability so that we can get online food shopping and safer shopping hours. So we stay in scared and running low on everything.	5	The government response was very bad at the beginning. I wasn't on the vulnerable list, and couldn't get any groceries. The council stepped in and they were fantastic! Got fresh food and everything, and they even checked in via phone every now and then.
	Reliance on friends and family to pick up provisions	3	It is very disempowering losing control over food shopping etc. Volunteers tend to make many mistakes in my experience so far, and everything is costing more since I can't see what's on offer.	3	Being more cautious in social encounters and spending a lot more time at home (minimising trips to supermarkets etc
<b>8) Employment and income</b>	Concern over job/ job loss	11	My partner and father are both self-employed so they still have to go to work or there will be no money coming in. My mother works part time and is a key worker but has decided to take annual leave as her employer will not furlough her, she will probably give her notice once her leave is up.	4	Support for students like myself with heart conditions are unable to work through being high risk and cant get and benefits due to student loan which hardly cover rent and bills as it is causing more worry through government not considering students especially in high risk categories who cannot work and have to be isolated to help the NHS



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**Figure 1:** Children and young people and parent responses from closed statement item relating to; Experiences(n=9), Information(n=4), Decisions(n=6) and Support needs(n=8) represented as number and percentage of respondents

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356 **Figure 2: A comment model of parental experience of COVID-19 crisis**