

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

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## **Abstract**

### **Purpose of the study**

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

### **Study design**

On-line survey design

### **Setting**

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

### **Patients**

Parents of children with CHD and CYP

### **Results**

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

### **Conclusions**

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

## Background

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

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

## Methods

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

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

## **Study participants**

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

## **Survey**

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

## **Data analysis**

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

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

## **Results**

### *Participants*

#### *Parents*

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

#### *Children and young people*

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

### **Closed item statements**

#### *Parent*

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

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

### *Children and young people*

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

### **Open text boxes**

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

### ***Virus***

#### ***Parents***

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

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

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

#### *Children and young people*

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

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

##### *Parents*

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

##### *Children and young people*

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



## **Information**

### *Parents*

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

### *Children and young people*

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

## **Support**

### *Parents*

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

### *Children and young people*

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

## **Decisions**

### *Parents*

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

### *Children and young people*

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

## **Discussion**

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

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

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

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

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

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

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

None

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**CONTRIBUTORS STATEMENT:**

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

- 286 1. Huang C, Wang Y, Li X, Ren L, Zhao J, Hu Y, et al. Clinical features of patients infected with  
 287 2019 novel coronavirus in Wuhan, China. *Lancet*. 2020 Feb 15;395(10223):497-506. PubMed PMID:  
 288 31986264. Pubmed Central PMCID: PMC7159299. Epub 2020/01/28. eng.
- 289 2. (WHO) WHO. Coronavirus disease (COVID-19) Pandemic Geneva: World Health Organisation,  
 290 Geneva; 2020 [cited 2020 6 May 2020]. Available from:  
 291 <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>.
- 292 3. Fact F. Can children transmit the new coronavirus to other people? London2020 [cited 2020  
 293 20 May 2020]. Available from: <https://fullfact.org/health/covid-19-in-children/>.
- 294 4. Ludvigsson JF. Systematic review of COVID-19 in children shows milder cases and a better  
 295 prognosis than adults. *Acta paediatrica* (Oslo, Norway : 1992). 2020 Jun;109(6):1088-95. PubMed  
 296 PMID: 32202343. Pubmed Central PMCID: PMC7228328. Epub 2020/03/24. eng.
- 297 5. van der Linde D, Konings EE, Slager MA, Witsenburg M, Helbing WA, Takkenberg JJ, et al.  
 298 Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis.  
 299 *Journal of the American College of Cardiology*. 2011 Nov 15;58(21):2241-7. PubMed PMID:  
 300 22078432. Epub 2011/11/15. eng.
- 301 6. Petersen S PV, Rayner M. Congenital Heart Disease Statistics. British Heart Foundation  
 302 Health Promotion Research Group  
 303 [Internet]. 2003.
- 304 7. Iacobucci G. Covid-19: all non-urgent elective surgery is suspended for at least three months  
 305 in England. *BMJ*. 2020;368:m1106.
- 306 8. Stephens EH, Dearani JA, Guleserian KJ, Overman DM, Tweddell JS, Backer CL, et al. COVID-  
 307 19: Crisis Management in Congenital Heart Surgery. *The Annals of thoracic surgery*. 2020 Apr 11.  
 308 PubMed PMID: 32302660. Pubmed Central PMCID: PMC7194669. Epub 2020/04/18. eng.
- 309 9. Robertson EG, Wakefield CE, Shaw J, Darlington AS, McGill BC, Cohn RJ, et al. Decision-  
 310 making in childhood cancer: parents' and adolescents' views and perceptions. *Support Care Cancer*.  
 311 2019 Nov;27(11):4331-40. PubMed PMID: 30880372. Epub 2019/03/19. eng.
- 312 10. Morgan JE, Phillips B, Stewart LA, Atkin K. Quest for certainty regarding early discharge in  
 313 paediatric low-risk febrile neutropenia: a multicentre qualitative focus group discussion study  
 314 involving patients, parents and healthcare professionals in the UK. *BMJ open*. 2018 May  
 315 14;8(5):e020324. PubMed PMID: 29764879. Pubmed Central PMCID: PMC5961608. Epub  
 316 2018/05/17. eng.
- 317 11. Wagland R, Bracher M, Drosdowsky A, Richardson A, Symons J, Mileshekin L, et al. Differences  
 318 in experiences of care between patients diagnosed with metastatic cancer of known and unknown  
 319 primaries: mixed-method findings from the 2013 cancer patient experience survey in England. *BMJ*  
 320 *open*. 2017 Sep 27;7(9):e017881. PubMed PMID: 28963312. Pubmed Central PMCID: PMC5623509.  
 321 Epub 2017/10/01. eng.
- 322 12. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*.  
 323 2006 2006/01/01;3(2):77-101.
- 324 13. Health RCoPaC. Guidance: Paediatric multisystem inflammatory syndrome temporally  
 325 associated with COVID-19 2020 5 May 2020. Available from:  
 326 [https://www.rcpch.ac.uk/resources/guidance-paediatric-multisystem-inflammatory-syndrome-](https://www.rcpch.ac.uk/resources/guidance-paediatric-multisystem-inflammatory-syndrome-temporally-associated-covid-19)  
 327 [temporally-associated-covid-19](https://www.rcpch.ac.uk/resources/guidance-paediatric-multisystem-inflammatory-syndrome-temporally-associated-covid-19).
- 328 14. Dubey S, Biswas P, Ghosh R, Chatterjee S, Dubey MJ, Chatterjee S, et al. Psychosocial impact  
 329 of COVID-19. *Diabetes Metab Syndr*. 2020;14(5):779-88. PubMed PMID: 32526627. eng.
- 330 15. Liu JJ, Bao Y, Huang X, Shi J, Lu L. Mental health considerations for children quarantined  
 331 because of COVID-19. *The Lancet Child & adolescent health*. 2020 May;4(5):347-9. PubMed PMID:  
 332 32224303. Pubmed Central PMCID: PMC7118598. Epub 2020/04/01. eng.

- 333 16. Van Lancker W, Parolin Z. COVID-19, school closures, and child poverty: a social crisis in the  
334 making. *Lancet Public Health*. 2020 May;5(5):e243-e4. PubMed PMID: 32275858. Pubmed Central  
335 PMCID: PMC7141480. Epub 2020/04/11. eng.
- 336 17. Larcher V, Brierley J. Children of COVID-19: pawns, pathfinders or partners? *J Med Ethics*.  
337 2020 Jun 5. PubMed PMID: 32503924. Epub 2020/06/07. eng.
- 338 18. Convention on the Rights of the Child, Stat. E/CN.4/RES/1990/74 (1990).  
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342 **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)

343 ASD: atrial septal defect; AVSD: atrioventricular septal defect, CHD: congenital heart disease; CYP: children and young  
344 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

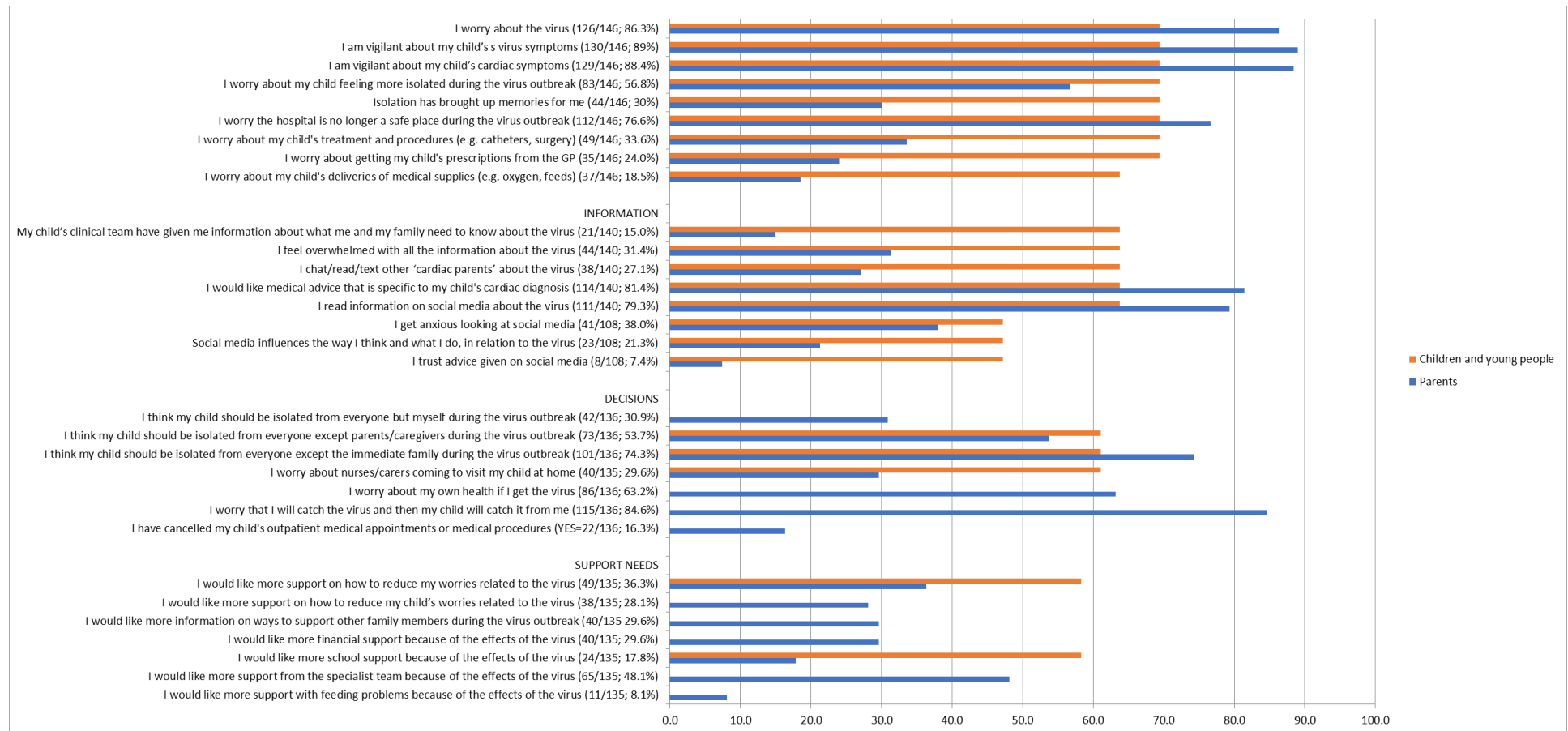
					stranger's house for the next 12 (possibly longer) weeks.
	Vigilance of symptoms of virus infection	1	Lucky enough we haven't experienced any signs or symptoms of the virus we just worry everyday.	3	I know that I'm at a higher risk than others and it's very worrying.
<b>2) Information, guidance and advice</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

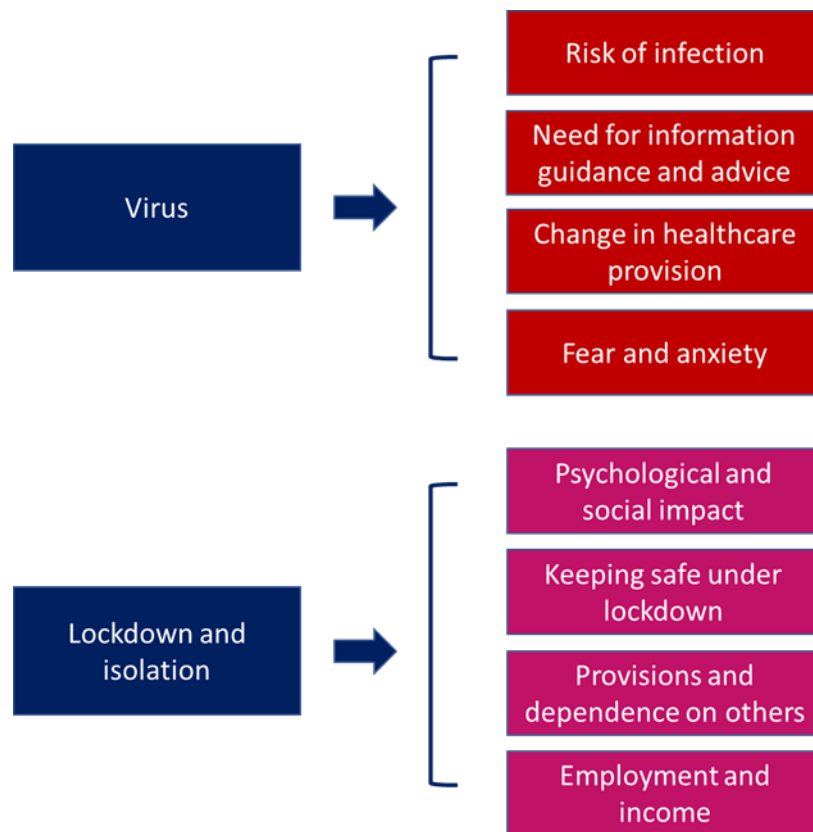
	Things could be worse	4	Great experience with my son, having been contacted and arranged surgery to close his VSD within a week.	4	Stay inside dont be stupid
	Separation if child becomes ill from rest of family	1	If he DOES get ill, I would like to know if I'm going to be allowed to come into hospital 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



**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



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