

Challenges experienced by families with a child diagnosed with COVID-19

Executive Summary

What is the COVID Wellbeing study?

The COVID Wellbeing Study is a mixed-methods cohort study led by the [Vaccine Uptake Group](#) at the Murdoch Children's Research Institute. It explores the impacts of COVID-19 on 342 children and their families who were tested for COVID-19 at the Royal Children's Hospital (RCH) during the first year of the pandemic between July-December 2020. All participants completed surveys, and 15 families of COVID-positive children were also interviewed about their experiences.

What does the research tell us?

The COVID Wellbeing study provides insight into how children and their families have managed a positive COVID-19 diagnosis in a child. As the pandemic progresses, there are growing concerns regarding the impact of repeated testing, social isolation, and days children have spent away from school and their friends. However, little has been documented about the stories of children and families who have lived through a positive diagnosis. This experience may cause trauma that could impact future management of their health and wellbeing.

This study provides an opportunity for these children and families to share their experiences. It shines a light on the importance of coordinated care, clear communication, community support and preventative mental health care for the recovery of children diagnosed with COVID-19.

This document presents interim findings from the COVID Wellbeing study at the Royal Children's Hospital.

It outlines the impact of a positive COVID-19 diagnosis on children and their families.

The COVID Wellbeing Study

The COVID Wellbeing Study is a mixed-methods longitudinal cohort study investigating the immediate and longer-term health and wellbeing impacts of COVID-19 on children and families. With a combination of surveys and interviews, we explore the clinical, psychosocial, educational, and economic impacts of COVID-19 on their families. Participants were recruited from those tested for COVID-19 at the Respiratory Infection Clinic at the Royal Children’s Hospital (RCH), Melbourne, during Victoria’s second wave, between July-December 2020.

A total of 342 children (47 COVID-positive, 295 COVID-negative) and their families were recruited. We asked all participants to complete a series of up to seven surveys over a 12-month period. These surveys are ongoing, and data collection will close in December 2021.

In addition to surveys, we conducted in-depth interviews with 15 families who had a COVID-19 positive child. Interviews explored families’ COVID-19 experiences and outcomes. Researcher field notes were also captured. We thematically analysed interview transcripts and researcher field notes.

At this time, this is the largest known cohort of COVID-19 positive children involved in a comprehensive wellbeing study in Australia.

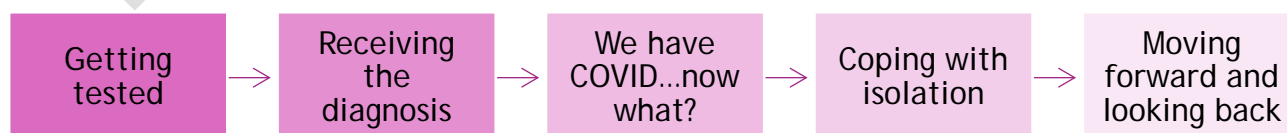
Challenges experienced by families with a child diagnosed with COVID-19

In this research brief, we focus on some of the challenges experienced by families with a child diagnosed with COVID-19. The interim findings presented here include some of the broad themes identified from the interviews. We also include quotes from parents, which have been de-identified.

It’s important to note that not all families experienced the challenges described here. Some families also described positive and neutral experiences. However, no family’s experience was entirely smooth sailing. This research brief shares people’s personal stories and highlights the expected and unexpected challenges families faced when their child tested positive for COVID-19.

The brief concludes with some recommendations to consider for those working in this area, to improve the experience of care and support for those families with children who have tested positive.

Figure 1: Families described challenges at different points in their COVID-19 journey



Getting tested

Challenges accessing testing

- Some parents reported having to attend multiple sites to get themselves and their child tested. Early in the pandemic, many sites would not test children under age 5. Some parents didn't know that adults could be tested at the RCH and so visited one site for parent and then subsequently another for child testing.

Fear and distress

- Some parents reported their child being afraid of the testing process
- Some parents indicated that the impact went beyond the testing period, with an impact on subsequent episodes of medical care.

"But whenever we drove past the Children's, she could almost start crying and now she's terrified to go to any doctor and even have medicine." (Participant 204)

Receiving the diagnosis

Shock and confusion

- Many families were shocked to get a positive diagnosis because no one in the household had COVID-19 symptoms. Some were only tested due to a family member being a close contact (e.g., worker at childcare centre, friend of child, client at work).

"I burst into tears because I wasn't expecting it. I was only sort of getting tested to tick a box to say, "[name of child] is fine to go to kindy". (Participant 214)

- Some families were so surprised to receive a positive diagnosis that they questioned whether it was accurate. Parents described replaying past events to try to identify the source of the infection, which they could never resolve. In some families, only the

child ever tested positive, adding to their uncertainty about the experience.

"I can't understand how she got sick. So, I think it was a false positive. But then also when I think about it being a false positive it makes me really angry because it led to a month of absolute hell. My marriage breaking down. So much drama with work." (Participant 286)

We have COVID...now what?

Guilt

- Several participants described feeling guilty that their children had contracted COVID-19, like they should have been able to protect them. This feeling was even more acute when the parent was the first case in the household.

"As a mum, I still find it really hard that inevitably I was the one that gave it to him ... there was absolutely nothing we could have done, and I know that but it just doesn't change the fact." (Participant 230)

What will other people think?

- Many participants didn't want to tell other people about the diagnosis. They were worried about being judged or treated differently.

"It's bad enough having to tell people that you're COVID positive, you just feel like a leper." (Participant 214)

"It's still not something I want to broadcast because people are too judgemental...I'm just scared they would treat me differently, like not want to come near me." (Participant 245)

- For those who did tell others about the diagnosis, this brought additional responsibilities and potential pressures as recipients wanted to know what they should do, or what they couldn't do.

- A few families described experiences of bullying. Some parents were bullied in the workplace, and one family's adolescent son was bullied by his classmates.
- Several people called their childcare providers to ensure the facility was closed. In many cases, their call preceded any notification from DH by days.

"They posted this message with all these alien emojis things, saying 'Guys, guys, [name of child] is positive!'...He was really upset." (Participant 204)

- A few parents felt that their privacy was breached by media reports that described specific characteristics of their child or family, such as the child's age. Some said that media descriptions of particular "clusters" made them feel othered.

"I think there was a lot of shaming around the super-spreaders language and stuff that was just so unhelpful." (Participant 262)

When contact tracing doesn't cut it

- Confusion and delays around contact tracing were a significant source of anxiety and stress for all families we interviewed.

"Just trying to process that your baby's got this potentially deadly infection and then having childcare call us saying, 'What's going on?' I don't know what's going on because DHHS haven't told us what's going on." (Participant 205)

- Many families felt that they had to take responsibility for contact tracing and notification of close contacts themselves. For some, this was because they wanted contacts notified immediately while others specifically noted that the Department of Health (DH) had insufficient resources and seemed overwhelmed.

"We gave [DH] all the information and I feel like they didn't use it. Even if they tried to use it, they didn't even contact everyone on our list. We gave them everything they wanted...that that was a bit of a letdown." (Participant 142)

Coping with isolation

Systemic issues compound distress

"I thought the staff were nice, I thought the procedures were disgraceful." (Participant 139)

- All participants described significant challenges associated with communication from the public health system, including mixed messages, inconsistent information, not receiving information or having to repeat the same information to public health workers.

"Each time someone different would call me and they wouldn't read the report and then they'd ask the same questions. And I got really angry at one stage and I said, 'Look, you need to communicate with all the rest of the people because this is wearing me out.'" (Participant 245).

- Many families received what they described as excessive, repetitive, or incorrect contact from public health workers. Some families were in the DH system multiple times, starting as close contacts and then becoming positive, or family members were not recognised as belonging to one household. This led to duplication of all daily communication with the public health team, disrupting family life. Participants tried to be understanding but were frustrated by unsuccessful attempts to correct the information in the system.

"We were getting these phone calls telling us the wrong information. Because they were treating us as close contacts [when we were actually positive.]" (Participant 262)

- Use of police and armed forces in uniform to enforce isolation drew unwanted attention to families. Some participants felt judged and unsupported, as these check-ins were done for legal / compliance reasons, rather than for their health.

"And then suddenly I look through the gate and there were three policemen with masks, standing there. That was a bit of a surprise for extremely law-abiding citizens...Different police turned up another two times on the same day." (Participant 204)

- Several participants noted that the advice they received from public health workers was inadequate or unrealistic, such as always wearing masks and gloves with the positive child. Isolation guidelines were particularly unrealistic when dealing with young positive children.

"They were like, 'Can't you be in a separate part of the house from her?' [laugh] Like no, she's three." (Participant 286)

Access to resources and support during isolation

- Participants described calling on friends and family to drop off items they needed while in isolation. Not everyone had people they could rely on in their area, and using systems like online grocery ordering could be expensive and difficult to access.

"It was very stressful just trying to get food in the house." (Participant 211)

How long are we stuck here?

- Many participants were unprepared for the actual length of the isolation period. They didn't realise there was a 14-day isolation period for the whole family *following* the end of symptoms of the child or other positive family members. This information was

provided up to 12 days into an isolation period or sourced via Google and confirmed only by contacting DH. Many ended up in isolation for 4 or more weeks, with one family isolated for 7 weeks. For those counting down the days, this extension was particularly difficult.

"So now we had to do another two weeks which kind of broke me." (Participant 143)

- Errors in record-keeping or data entry sometimes extended participants' isolation period, compounding frustration.

"[DH] rang and said, 'Sorry, there's been a delay in getting to you. We didn't have you guys down as being close contacts with [name of child]. You can't actually start your isolation period until [name of child] has been cleared.' And that was just like a punch in my gut and I started crying and I was like, 'This is crazy.'" (Participant 214)

Moving forward and looking back

- Some participants described lingering anxiety and stress for themselves and/or their children related to their COVID-19 experience. Indications of mental health impacts for children included difficulty sleeping and nightmares, controlling behaviours around food, not discussing or blocking out memories of COVID, and withdrawing from friends.

"He's become really, really controlling of his food and really, really health conscious, but to a point that I actually think he's a bit unhealthy. He's lost weight...As you could sort of understand from the way he handled being positive and he's so self-managing and self-controlling, in a way." (Participant 204)

- For parents, lingering effects included anxiety, shame, and fear of reinfection.

"Afterwards my anxiety was like a thousand percent. I didn't step foot in a shop for probably six weeks." (Participant 261)

Implications and recommendations

Communication and support

- Importance of coordinated, reliable and accessible information and communication.
- Clear, simple, comprehensive and family focused instructions on what to do immediately after result and then in subsequent key time periods.
- Access to preventative psychosocial care at diagnosis to support families to cope well with the physical and psychological impacts of the diagnosis. While illness is generally mild, the potential for impacts on child and family wellbeing are not insignificant.

Systems

- Coordinated public health care response for families impacted by a positive diagnosis.
- Public health messaging that leverages fear or implies that positive cases are rule-breakers can cause stigma and distress.
- Build/maintain confidence and trust in healthcare and government systems.

Limitations to consider

- Children in our sample were mild COVID-19 cases; some with no or minimal symptoms, or for very short time periods. Families did not

experience children having to be hospitalised post-diagnosis.

- Testing period occurred during early stages of Melbourne adapting to COVID-19 pandemic. Participants were experiencing systems likely being developed, implemented and refined in real-time.
- Experiences changed over time.
- These are interim findings presented to facilitate access to key information. Additional analyses are ongoing.

Resources for families

- RCH Kids Health Info - [Supporting your child to cope with the COVID-19 pandemic](#)
- RCH Kids Health info podcast - [COVID-19 what parents need to know](#)
- Raising children network - [Coronavirus: Family Guide](#)
- Victorian State Government - [Advice for parents, carers and guardians](#)
- Kids Helpline - [Your guide to everything coronavirus](#)
- Dr Ellie Aitkins (clinical psychologist at St George's Hospital UK) - [How to deal with stress about COVID-19 A Guide for Children and Young People](#)
- Raising children - [Raising learners podcast](#)
- Murdoch Children's Research Institute - [Parenting in the age of coronavirus podcast](#)
- Lifeline Australia - [We're here for you](#)
- Beyond Blue - [Coronavirus Mental Wellbeing Support Service](#)

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