

Working with communities to mitigate the collateral impact of COVID-19 on children and young people

Charles Coughlan ^{1,2}, Arpana Soni ¹, Hanan Ghoneim,³ Kiera Ghoneim,³ Phoebe Rutherford,¹ Rianne Steele,¹ Meerat Kaur,⁴ Mando Watson ¹

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¹Connecting Care for Children, Department of Paediatrics, Imperial College Healthcare NHS Trust, London, UK

²School of Public Health, Imperial College London, London, UK

³Citizen, London, UK

⁴National Institute for Health Research Applied Research Collaboration North West London, London, UK

Correspondence to

Dr Mando Watson; mando.watson@nhs.net

INTRODUCTION

Less than a year after it was first described, COVID-19 has had a profound impact on children and young people (CYP) and their families. While CYP have been relatively spared from severe clinical manifestations of COVID-19,¹ there are growing concerns about the collateral impact of the pandemic on their health, well-being and development.² Health services have adapted to meet these challenges, but patient and public involvement (PPI) in research, policy-making and service reconfiguration has been largely overlooked.³ The complex consequences of the pandemic cannot be addressed sustainably without community engagement, which takes on renewed importance in our era of 'fake news' and scepticism towards authority figures. How can we know what support patients and carers want, or what they need their future health systems to look like, without asking them directly? Meaningful engagement benefits all; health professionals can improve mutual understanding by developing equitable relationships with citizens, and this helps citizens to provide peer-to-peer support and better navigate complex local health systems.⁴

As a group of citizens, clinicians and researchers, we have worked together to mitigate the collateral damage of COVID-19 on CYP living in North West London (NWL). We have built on existing relationships with members of our communities to understand concerns and inform service co-design. Here, we explore the concerns of CYP and their carers and highlight examples of good practice to inspire others to strengthen PPI as the COVID-19 pandemic evolves.

WHAT ARE THE CONCERNS OF PARENTS, CHILDREN AND YOUNG PEOPLE?

While several studies have highlighted the low incidence and transmission of SARS-CoV-2

among children,^{1,5} many CYP and carers have struggled to gauge levels of personal risk. In a survey of 1500 Americans, young people aged 18–34 years believed they were more likely to contract COVID-19, require hospitalisation and die than adults over 70 years of age.⁶ In the UK, following widespread reports of poor disease outcomes, fears of the virus are particularly prominent among parents of CYP belonging to racial minorities.⁷ Further confusion has resulted from the chaotic process of identifying children who need to shield from COVID-19.⁸ In our experience, many parents have felt compelled to keep their children at home as a means of regaining control during a time of uncertainty.

Contrary to media tropes about self-obsessed young people, many CYP are worried about vulnerable friends and relatives, the strain on health services and the economic consequences of the pandemic.⁷ Other concerns include the impact of the pandemic on education and work.⁹ Two-thirds of young people are worried about their mental health, compared with just 20% of the general population,¹⁰ and parents have reported increased anxiety and depression, sleep disturbances and mood swings in their children.¹¹

HOW HAVE WE WORKED WITH COMMUNITIES TO ADDRESS THESE CONCERNS?

Community Voices: Conversations for Change is a collective of individuals from community, National Health Service (NHS), innovation and research organisations. It hears what matters to people and gathers stories from communities in NWL in their own words. The collective has heard that concerns have spiralled due to confusing guidance, slow and culturally unaware communication and the spread of misinformation. This connects to frustrations among our communities about



the ongoing impact of structural racism, widening health inequalities and the quality of the care they receive. As child health professionals and researchers, we have a responsibility to reflect on these issues as parents' and children's lived experiences sit at the intersection of race, gender and poverty. With permission, these stories have been shared with local NHS organisations, such as Connecting Care for Children (CC4C), to inform service improvements.

CC4C is a paediatric integrated care organisation that improves child health by building connections between patients, families and professionals. CC4C's Child Health GP Hub model is centred on improving access to specialist advice; creating multi-disciplinary teams; and engaging patients, families and the public.¹² Prior to the COVID-19 pandemic, CC4C regularly sought the views of local parents and young people attending primary care centres on their child health priorities. Parents and young people were invited to become 'Champions' for child health at their general practice and address their concerns—such as childhood obesity—through grass-roots campaigns.¹³ During the COVID-19 lockdown, CC4C maintained this volunteer network through weekly calls. Champions' concerns formed the basis of a series of webinars, which allowed parents and young people to put questions to local paediatricians. Webinars were promoted by local health and third sector partners and one session was cohosted by young people, giving prominence to their voices, and improving uptake by members of seldom-heard groups. **Box 1** highlights the tumultuous experiences of one local young person during the COVID-19 lockdown.

CC4C also worked with a local volunteer (HG) to design information bundles for parents, covering childhood illness with COVID-19, access to emergency services and immunisations (online supplemental materials 1–3). These spread rapidly through local social media networks

because they were highly relevant to parents, by design. HG has said that her involvement in coproducing materials for her community has 'given [her] something to focus on other than the nightmare we're living in'. Other resources produced by CC4C with relevance to child health during the COVID-19 pandemic can be found in the online supplemental materials 4–6.

HOW CAN WE PROMOTE SUSTAINABLE ENGAGEMENT WITH PARENTS AND CYP DURING COVID-19?

In the UK, CYP have been excluded from asking questions in government briefings.¹⁴ This may stem from a misplaced, paternalistic desire to protect children from the realities of the pandemic. However, we must be open and honest with CYP to help them to understand the risks posed by the virus.¹⁵ Our recent experience suggests that citizens value direct involvement in webinars and codesigning resources as it provides them with a sense of control during a crisis. Young people can participate directly in research as peer researchers, giving them new skills and simultaneously enhancing access to seldom-heard groups.¹⁶ More equitable relationships are key; communities will engage if benefits are mutual. Careful attention must be paid to the human and financial resources needed for engagement and providing neutral physical and virtual spaces where communities, health professionals and researchers can work together. Initiatives such as Community Voices and a citizen-led approach to health and care in Wigan¹⁷ confirm the value of participatory research and community engagement in driving sustainable, patient-centred change.

CONCLUSIONS

CYP have experienced substantial collateral damage from the COVID-19 pandemic. Disturbingly, they have been sidelined during this crisis. We must take this important opportunity to enhance their voices and those of their families to reshape health and research priorities around patient and carer perspectives.

Twitter Meerat Kaur @kaumee and Mando Watson @mandowatson

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Box 1 Patient perspective

I was diagnosed with juvenile idiopathic arthritis in Egypt in October 2019. In November 2019 I was referred to a specialist hospital to confirm the diagnosis. I had my first appointment but after this we went into lockdown and so everything was put on hold except my pain. It was really difficult as all my support was gone and my condition started to worsen as I developed new symptoms.

My mental health was affected as I started to feel there was no purpose to life anymore. I used to socialise and volunteer a lot before lockdown, so not being able to see my friends was quite hard. I was very scared of what would happen if I caught COVID-19 as my immune system is compromised. I used to have a lot of down days and I was on an emotional roller-coaster. The easing of lockdown meant I could go to the hospital for various tests. At my first visit, I was convinced I would catch COVID-19 but I have now been five times and I haven't. More importantly I've been able to meet my close friends. I want to go back to school, I want life to go back to normal. But other people have been going to parties and will be getting public transport to school, so is it even safe to go back?

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ORCID iDs

Charles Coughlan <http://orcid.org/0000-0003-3907-3859>

Arpana Soni <http://orcid.org/0000-0003-1685-6738>

Mando Watson <http://orcid.org/0000-0001-6372-1321>

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