

Young people's views on their role in the COVID-19 pandemic and society's recovery from it

Vic Larcher,¹ Mariana Dittborn,¹ James Linthicum,¹ Amy Sutton,² Joe Brierley ,¹ Christopher Payne,² Hannah Hardy,² On behalf of GOSH Young People's Forum

¹Paediatric Bioethics Centre, Great Ormond Street Hospital For Children NHS Trust, London, UK

²Young people's Forum, Great Ormond Street Hospital Biomedical Research Centre, London, United Kingdom

Correspondence to

Dr Joe Brierley, Paediatric Intensive Care & Bioethics, National Institute for Health Research Great Ormond Street Hospital Biomedical Research Centre, London WC1N 3JH, UK; joe.brierley@gosh.nhs.uk

Received 25 June 2020

Revised 5 August 2020

Accepted 7 August 2020

Published Online First

31 August 2020

ABSTRACT

Objective There has been little formal exploration of how young people see their role in the COVID-19 pandemic.

Design/setting Focus-group discussion with 15 Children's Hospital Young People's Forum members (23/5) to explore their perspective on the impact of COVID-19 on both their lives and those of their community, on school closures, and the role they wished to play in society's recovery from the pandemic. Audio recordings were transcribed verbatim using NVivo Software and analysed using an inductive thematic analysis approach.

Outcome Four major themes identified: (1) Awareness of pandemic's impact on others: participants showed mature awareness of the effects on broader society, especially the elderly, socially disadvantaged and parents. (2) Perceived impact on their own lives: principal concerns were the educational and practical repercussions of school closures and social isolation, including effects on educational prospects. (3) Views about school reopening: young people understood the broader rationale for school reopening and were generally positive about it, but expressed concern about their safety and that of others. (4) Communication issues: a need for clear, concise, understandable information readily accessible for young people was expressed. Up to now, they felt passive recipients rather than participants.

Conclusion Young people were concerned about their future, their family and broader society, consistent with a high level of moral development. They want to be active participants in social recovery, including concepts around return to school but require appropriate information and a means by which their voices can be heard. The alternative suggested roles as pawns or pathfinders were discounted.

INTRODUCTION

In the UK and elsewhere, the response to the COVID-19 pandemic has been 'guided by the science'.¹ But the implication that there is one form of science whose facts should guide policy is erroneous, since medical, social and economic disciplines are all involved. Moreover, science is not value-free, since inevitable disparities in scientific advice need to be resolved by judgements that are value-driven and which need to take into account the views of those involved if ethical principles of equal concern and respect are to be satisfied.²

The wider psychosocial and economic consequences of the pandemic are fast emerging.^{3 4}

What is already known on this topic?

- ▶ SARS-CoV-2 has not severely clinically impacted children compared with other groups, yet they have been profoundly affected by control measures, for example, social distancing and school closures.
- ▶ The views of young people on the effects of the pandemic on society, and their role in recovery for it have been little explored.
- ▶ Roles as partners, pawn or pathfinders in society's recovery from the pandemic have been suggested for young people; it is unknown which they think suitable.

What this study adds?

- ▶ The main concerns of young people about the pandemic are its effects on others (known to them; the abstract vulnerable) and on their own education/future.
- ▶ Young people do not consider roles as pawns or pathfinders in society's emergence from the pandemic as suitable, preferring to be partners.
- ▶ Young people felt recipients rather than participants in the pandemic process; they need appropriate accessible information and means by which their voices can be heard.

Although young people (YP) have suffered less as a direct result of COVID-19 disease than other vulnerable groups, for example, the elderly and BAME (Black, Asian and Minority Ethnic) community,⁵⁻⁷ the indirect impact on them has been marked.⁴ Perhaps of more significant concern is the educational and psychosocial effects of physical distancing, social isolation and school closures on children's welfare.^{8 9} Reopening of schools is, therefore, a key element in the recovery process, because of the benefits it brings, but it remains a matter of dispute.

The broader role YP might play in the recovery process needs to be explored since they will, as adults, bear the economic and psychosocial consequences of the pandemic.¹⁰ Yet there has been little formal exploration of how they view their roles in this process or of how their voices might be heard. To begin to address this, we explored the views of YP on the impact of the pandemic on both their lives and those of their community, on school closures and of the role they wished to play in recovery.



© Author(s) (or their employer(s)) 2020. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Larcher V, Dittborn M, Linthicum J, et al. *Arch Dis Child* 2020;**105**:1192–1196.

METHODS

We conducted an audio-recorded focus-group discussion with 15 available members (11–18 years) of the Hospital Young People's Forum (YPF) via Zoom videoconference on the afternoon of the 23 May 2020. The session lasted 70 min with a 15 min break after the first half-hour. The YPF represents patients aged 10 to 21 cared for by the hospital. Participants had been provided with the Bioethics team's recent *JME* paper/blog on the role of YP during the pandemic.¹⁰ The discussion was guided by three questions: (1) How can YP get their views heard during a pandemic? (2) What do YP think about the return to schools? (3) What do YP think about the effects of the pandemic?

Ethics approval was not required according to HRA (Health Research Agency) Standard Operating Procedures for this urgent video-conference focus-group discussion about the COVID-19 pandemic, though AS ensured all children and their parents were fully informed and consented to participation as per YPF processes.

Audio recordings were transcribed verbatim using NVivo Software and analysed using an inductive thematic analysis approach.¹¹

RESULTS

Four major themes with subthemes were identified: YP comment: boxes 1 and 2.

1. *Awareness of the impact on others*: Participants showed clear recognition of the effects of the pandemic and the imposed control measures on broader society, focusing mainly on three groups: the elderly, socially disadvantaged and parents.
 - i. Elderly and communication and technology challenges: Participants were all technology proficient, being able to join a video-conference forum, but had experienced communication challenges with their more elderly relatives who often lacked skills to use online communication means: (P5). Participants recognised this as a broader problem, including for those organisations that would typically support older people who were themselves now facing communication problems.
 - ii. Socially disadvantaged: Participants were aware of challenges posed by social inequalities on those from underprivileged backgrounds. Notably, they mentioned that students who lacked the required devices for home-schooling needed support and the provision of appropriate, updated and dynamic materials: (P7).
 - iii. Challenges for parents: Participants discussed how competing responsibilities posed by school closure and working from home was challenging for their parents, who often lacked teaching skills and the time needed to support children with homework: (P3).
2. *The perceived impacts on their own lives*
 - i. School closure: Many felt that home-schooling and online learning had been an overwhelming experience produced by such factors as the new format, the lack of peer interaction for discussion and education and lack of proper support from their teachers. Participants expressed how support received was inadequate and slow regarding submission deadlines: (P5).
 - ii. Suspended grades: For those preparing for A-levels, with the need to obtain specific grades to progress to university, cancellation produced feelings of disappointment, impotence and uncertainty about their future, for which they had been working hard and looking forward. Lack

Box 1 Synthesis of themes and subthemes from Young People's forum focus-group discussion (i)

1. *Awareness of the impact of the pandemic on others*

- i. Elderly and communication; technology challenges
"So, all of my grandparents are very social, but I think I found staying in quite hard, especially because they don't understand technology as well [...]. So, none of them would be able to face time." (P5).
- ii. Socially disadvantaged
"They kind of came out and asked who had the provision to actually access the Internet to do work. And I think for the people who didn't, they were given textbooks. And to me, that seems a little bit outdated and something that maybe isn't too useful because that's not a constant stream of information." (P7)
- iii. Challenges for parents
"But obviously, our parents don't know everything about things. So, then we try, and you google. But then when Google doesn't give you the answer, then you rely on your parents. But your parents can't really teach you anything. So, you kind of feel bad because you can't do anything because you don't understand it, but they don't understand your work either." (P3)
- iv. Schools' staff: this is included under school reopening concerns

2. *The perceived impacts on their own lives*

- i. School closure
"We have been almost overwhelmed. I know I have. With the amount of work that's been set all at one time. And a lot of the teachers don't respond when you ask them for assistance with things we might be stuck on." (P5)
- ii. Suspended grades
"Oh, I was going to have my A-levels this year, but obviously they got cancelled and it, kind of feels like the sort of rite of passage that kind of got them. Yeah. For me that you don't get to go through, like because I want to do medicine. I've done so many things for the past two years. Just as often leads up to and it's like you've built up all this momentum. But the end result and like thought of going through exams or just disappear so you don't have that place of relief for this sort of energy and everything that's been building up." (P14)
- iii. Social isolation
"So, it might be very hard for some people because we can't see our friends anymore. And I know that I haven't got much family, so my friends are more like my family and I depend on them. It's not being able to have that human contact in person is really hard." (P9)

of clear guidance and information about how this will be managed contributed to concerns: (P14).

- iii. Social isolation: Regarding social isolation, participants mentioned difficulties with being unable to socialise face-to-face with their peers, with whom they would normally share their personal struggles, as expressed by this participant: (P9). Participants also expressed challenges produced by the interruption of their usual coping mechanisms, such as sport or music activities. While some of them were adapting readily to new online formats, there were concerns about the significant amount of screen time to which they were now exposed.
3. *YPs' views about school reopening*

Box 2 Synthesis of themes and subthemes from Young People's forum focus-group discussion (ii)

3. School reopening

i. Rationale

"I don't think until MPs are sitting together in the House of Commons, I don't think we should be sitting together in school just because we're younger and we aren't at risk of having a more serious infection, doesn't mean we should be the first to have to fully go back and reintegrate. I don't think that is a really safe thing to do because that is a blanket." (P5)

ii. Concerns

"There's obviously a lot of concerns about how the risk of infection will be strictly managed all day long because I know like at some schools there's key workers kids who all go in, and it's really good the social distancing. All-day long. But at the break and lunchtimes, there's no social distancing at all. So, all the kids go back together and then at pick up. All the parents are together as well." (P12)

iii. Age groups' particular issues

"I was kind of a forgotten group of uni students in the sense that all unis have different policies about what they're doing. Some are holding their exams; some aren't. And then the question of the future, they sort of forget the fact that we're all racking up nine thousand pounds every year, even if we're not allowed to go back." (P15)

4. Communication with YP

i. Right to information—tailored

"So, even if it's presented in a different way, you're entitled to the same information in life as an adult should be." (P2)

ii. Threats related to available information

iii. Linear communication model—YPs as recipients only

"They're not listening to children, young people much at the moment." (P1)

iv. YP's participation in the decision-making process

"I think that's a general view at the moment that it's going to affect this generation most with all the debt and everything that's building up out of this." (P1)

"Yeah. I was thinking maybe one way that children and young people could get their words heard was maybe a schools or youth group sent out like a Q and A. And then the answers and their opinions were collaborative and maybe sent to MPs or somebody higher up." (P7)

- i. Rationale: Views toward school reopening were variable. Some thought that this was necessary to allow parents to go back to work. In contrast, others considered this unsafe as children would be the first in society to have close contact with other people: (P5)
 - ii. Concerns: Various anxieties were expressed about school reopening related to impracticable infection control measures, including social distancing steps, that would lead to risks for staff and any students' family members who might be at high risk of severe disease: (P12).
 - iii. Age groups' particular issues: Most comments were concerned with year 10–12 returnees, rather than younger children, but a view concerning the impact on university students was also expressed: (P15).
4. *Communication with YP*
- i. Right to appropriately tailored information: Participants agreed that YP had the right to receive information about

the pandemic, but acknowledged the challenges associated with adapting it to recipients' needs and different age groups. However, they felt that comprehensive details should be provided while avoiding complicated wording and lengthy and confusing content: (P2).

- ii. Problems related to available information: Participants mentioned several issues with how information was being presented, which they felt was not explicitly aimed at a YP audience. Many knowledge resources provided overwhelming and confusing amounts of data, with inconsistencies between government/institutions' official reports and what they saw shared on social media. However, they also identified the risk of fake news on some platforms, which concerned them due to the considerable uncertainty it could generate among YP.
- iii. Linear communication model—YP as passive recipients: Information was reportedly received from different channels, especially from schools: "[...] We've also been receiving weekly updates from the college." However, only a few mentioned that they had opportunities to express their questions and opinions. Most participants agreed with the feeling of not having a voice during the pandemic or during the recovery process: (P1).
- iv. YP's participation in the recovery process: Many expressed the view they should be part of this process, as they are and will be directly affected by the pandemic in multiple aspects of their current and future lives: (P1). They suggested various ways in which YP's voices could be heard: from looking at what YP are currently discussing and their opinions on social media and other platforms, in collaborative or national surveys by active representation and participation in the Youth Parliament, and in events like the current forum: (P7).

We asked the YP to write a paragraph about being one of two YP authors on the paper, to reflect their contribution to the paper—judging only two proved incredibly hard, therefore we have elected to share these as an online supplementary file. (YP Paragraphs)

DISCUSSION

The discussion held in this focus group with 15 YP provided remarkable insight on their awareness of moral issues concerning themselves, their families and the wider community, consistent with higher levels of moral development. They demonstrated knowledge of themselves over time in respect of future ambitions and need for education. Additionally, participants expressed willingness to participate in the response and recovery process by actively looking for both information sources and means to voice their views. However, most acknowledged the lack of opportunities to express their opinions and actively participate in the process.

The UN Convention on the Rights of the Child (UNCRC)¹² and the UK Children Act¹³ provide for the rights of children to express their views on matters that concern them, and for those views to be given due weight in accordance with their age, maturity and understanding. Professional bodies such as the General Medical Council and Royal College of Paediatrics and Child Health¹⁴ have sought to involve YP in discussions about policy and other matters.¹⁴ The reason for YP's voices not being considered in the pandemic response and regarding recovery measures is unclear. It might be due to persistent notions of incomplete moral development and agency in this group, even though some children have shown the capacity for self-directed acts of

kindness and altruism.¹⁵ Participants in this focus group showed great ability to understand complex issues and, more importantly, expressed the need and willingness to actively participate, supporting the Social and Legal commitments to them represented in the above international and national standards/laws.

Although the participants were sophisticated in terms of their medical knowledge, gleaned from past experiences and participation in the YPF, they felt that the information that they had received was complicated, confusing and in some instances, contradictory. If this was the case for this group, it seems highly likely that it would apply to an even greater extent to those who lacked their experience and knowledge. Again, this group demonstrated concern for others by suggesting strategies to alleviate this problem. This issue requires urgent attention with lack of transparent, appropriately presented and complete information impeding YP's participation in this process.

Initially, national debates about the COVID-19 pandemic were primarily concerned with discussions about the medical science including the direct effect of the virus on vulnerable individuals and maintenance of critical care capacity, so little involved YP who were not perceived likely to be significantly affected. However, this is no longer the case given the recent identification of the paediatric multisystem inflammatory syndrome temporally associated with COVID-19,^{15 16} and the highlighting of the socioeconomic consequences of physical distancing, social isolation and school closures, and of now a recovery to the 'new normal'. Children's issues, including how we must mitigate the profound detrimental effects on them as a social priority, is finally becoming clear.

Return to school has been an essential element in this because of the significant interruption of education that has occurred, the vital part played by schools in the psychosocial support and protection of vulnerable children, and the freeing of parents to contribute to the economy. Participants in the focus group were aware and concerned that YP and younger children have been and will continue to be indirectly affected by the pandemic and the control measures imposed, notably social isolation, school closure and for older participants, the impact of suspended grades.

After reading the *JME* paper about their potential role as pawns, pathfinders or partners in the recovery process, the comments made by the YP provided a clear indication of the position that they would wish to play in response to the pandemic. Comments about the limited provision of relevant and accessible information, together with the almost complete lack of consultation of children throughout were indicative of passive 'pawn' role insofar as others made decisions on their behalf in which they had no active part.¹⁰ Concerns expressed about their safety and that of others, together with the view that others should be taking similar risks suggested that they did not regard the 'pathfinder' role,¹⁰ even with safeguards, an attractive one. In contrast, general support for a more active partnership role was clear; this is undoubtedly consistent with pre-existing standards, especially the UNCR.

To be clear, the need to make urgent difficult decisions in the national interest is a crucial role of government and we do not seek some plebiscite of those most affected (ie, teachers, YP and parents regarding school closures) before urgent decisions are taken. But we do argue that consultation of such groups ought to occur as soon as possible after any urgent action, and indeed before if there is time.

We wish to highlight a few strengths and limitations to this study. There was a broad range of participants, all actively involved, which allowed the YPF to eloquently contribute to a

little explored, hot topic affecting them. The presence of the authors of the provided paper might have made it more difficult to voice disagreement, though this was not the author's experience. Although the aim was not to look for representativeness, this is a particularly educated and informed group in terms of prior involvement in, and experience of, child health issues. Therefore, it is unclear how generalisable to other YP our findings are.

CONCLUSIONS

There is a lack of information concerning the role of children and YP in the COVID-19 pandemic response. From this limited study, it seems clear that YP have relevant concerns about themselves (especially their future), their family and broader society. They feel that they should have an active part to play in both return to school and the recovery process, though they have had little mechanism as yet to do so. They do not see themselves as either pathfinders or pawns, but rather partners in society's emergence from the pandemic.

Twitter Vic Larcher @viclarcher

Acknowledgements GOSH Young People's Forum Members who participated, but are not authors: Archie Hadfield, Rose Dolan, Ella Campbell, Grace Shaw-Hamilton, Hannah Richardson, Josh Hardy, Kanya Mandhar, Olivia Burlacu, Ryan Aoudjet, Scarlet Davies, Shelby Davies, Tabitha Owen.

Contributors JB conceived the project after email exchange with the Editor in chief. VL and JB wrote the *JME* paper and blog which the YPF read before the focus group. AS leads the YP, and with MD and JL organised the focus group and contributed to the paper. MD and VL transcribed and JB, VL and MD analysed the data. All YP were invited to comment on why they might be authors, and we think they are all so good we include as an addendum. All authors approved the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. The data consist of the full transcripts, the audio recording has been destroyed.

This article is made freely available for use in accordance with BMJ's website terms and conditions for the duration of the covid-19 pandemic or until otherwise determined by BMJ. You may use, download and print the article for any lawful, non-commercial purpose (including text and data mining) provided that all copyright notices and trade marks are retained.

ORCID iD

Joe Brierley <http://orcid.org/0000-0003-0919-6882>

REFERENCES

- 1 Fritz Z, Huxtable R, Ives J, *et al*. Ethical road map through the covid-19 pandemic 2020:1–2.
- 2 Department of Health and Social Care. Guidance: Responding to COVID-19: the ethical framework for adult social care [Internet], 2020. Available: <https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care#contents>
- 3 Douglas M, Katikireddi SV, Taulbut M, *et al*. Mitigating the wider health effects of covid-19 pandemic response. *BMJ* 2020;369:m1557.
- 4 Green P. Risks to children and young people during covid-19 pandemic. *BMJ* 2020;1669:1–2.
- 5 White C. Coronavirus (COVID-19) related deaths by ethnic group, England and Wales: 2 March 2020 to 10 April 2020 2020:1–10.
- 6 Lu X, Zhang L, Du H, *et al*. SARS-CoV-2 infection in children. *N Engl J Med* 2020;382:1663–5.
- 7 Bialek S, Gierke R, Hughes M, *et al*. Coronavirus disease 2019 in children — United States, February 12–April 2, 2020. *MMWR Morb Mortal Wkly Rep* 2020;69:422–6.
- 8 Orben A, Tomova L, Blakemore S-J. The effects of social deprivation on adolescent development and mental health. *Lancet Child Adolesc Health* 2020;4:1–7.
- 9 Viner RM, Russell SJ, Croker H, *et al*. School closure and management practices during coronavirus outbreaks including COVID-19: a rapid systematic review. *Lancet Child Adolesc Health* 2020;4:397–404.

- 10 Larcher V, Brierley J. Children of COVID-19: pawns, pathfinders or partners?. *J Med Ethics* 2020;46:508–9.
 - 11 Braun V, Clarke V. Using thematic analysis in psychology 2019.
 - 12 United Nations General Assembly. Convention on the rights of the child 1989.
 - 13 Uk public General acts. children act 1989 1989.
 - 14 Wood D, Turner G, Straw F. Not just a phase. A guide to the participation of children and young people in health services 2010.
 - 15 Whittaker E, Bamford A, Kenny J, *et al*. Clinical characteristics of 58 children with a paediatric inflammatory multisystem syndrome temporally associated with SARS-CoV-2. *JAMA* 2020;324:259.
 - 16 Ramcharan T, Nolan O, Lai CY, *et al*. Paediatric inflammatory multisystem syndrome: temporally associated with SARS-CoV-2 (PIMS-TS): cardiac features, management and short-term outcomes at a UK tertiary paediatric Hospital. *Pediatr Cardiol* 2020;91:1–11.
-