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Biobanking and consenting to research: a qualitative thematic analysis of young people's perspectives in the North East of England

Fabian J. S. van der Velden^{1,2†}, Emma Lim^{1,3,4†}, Lily Gills⁵, Jasmin Broadey⁶, Louise Hayes³, Eve Roberts⁴, Jack Courtney⁵, Joanne Ball⁵, Jethro Herberg⁷, Rachel Galassini⁷, Marieke Emonts^{1,2*} and DIAMONDS consortium⁷

Abstract

Background Biobanking biospecimens and consent are common practice in paediatric research. We need to explore children and young people's (CYP) knowledge and perspectives around the use of and consent to biobanking. This will ensure meaningful informed consent can be obtained and improve current consent procedures.

Methods We designed a survey, in co-production with CYP, collecting demographic data, views on biobanking, and consent using three scenarios: 1) prospective consent, 2) deferred consent, and 3) re-consent and assent at age of capacity. The survey was disseminated via the Young Person's Advisory Group North England (YPAGne) and participating CYP's secondary schools. Data were analysed using a qualitative thematic approach by three independent reviewers (including CYP) to identify common themes. Data triangulation occurred independently by a fourth reviewer.

Results One hundred two CYP completed the survey. Most were between 16–18 years (63.7%, $N=65$) and female (66.7%, $N=68$). 72.3% had no prior knowledge of biobanking ($N=73$).

Acceptability of prospective consent for biobanking was high (91.2%, $N=93$) with common themes: 'altruism', 'potential benefits outweigh individual risk', 'frugality', and '(in)convenience'.

Deferred consent was also deemed acceptable in the large majority (84.3%, $N=86$), with common themes: 'altruism', 'body integrity' and 'sample frugality'. 76.5% preferred to re-consent when cognitively mature enough to give assent ($N=78$), even if parental consent was previously in place. 79.2% wanted to be informed if their biobanked biospecimen is reused ($N=80$).

Conclusion Prospective and deferred consent acceptability for biobanking is high among CYP in the UK. Altruism, frugality, body integrity, and privacy are the most important themes. Clear communication and justification are paramount to obtain consent. Any CYP with capacity should be part of the consenting procedure, if possible.

Keywords Paediatrics, Biobank, Consent, Assent, Children and young people

[†]Fabian J. S. van der Velden and Emma Lim contributed equally to this work.

*Correspondence:

Marieke Emonts

marieke.emonts@newcastle.ac.uk

Full list of author information is available at the end of the article



Introduction

Biobanking has become increasingly common, in biomedical research, and within in paediatrics [1, 2]. Biobanks are valuable repositories of human biospecimens, associated data and technological infrastructure [3]. Biobanks provide an important resource for biomedical research in the development of new diagnostic methods, treatments, determinants of disease in various contexts.

The success of a biobank relies on the willingness of people to donate samples, and incurs many ethical, social and legal challenges. Biobanking raises unique issues with regards to consenting procedures, sample donation, data confidentiality and privacy [4–6]. There is little guidance around the ethics of biobanking, however the Council for International Organizations of Medical Sciences (CIOMS) has published guidelines [7], addressing issues around collection, storage, and use of biological materials and related data in health-related research. They provide general and specific considerations for biobanks, including governance for keeping participants informed of research outcomes, consent, withdrawal of consent and opt out procedures, and unexpected or unsolicited findings alongside the storage and use of genetic material. Ashcroft and Macpherson [6] identified further ethical concerns including *“misconceptions about biobanking and distinctions between research, diagnostics, and treatment; unknown consequences of, and harms to, individual and collective donors of materials or information and socioeconomic inequities that impinge on donor understanding and voluntariness and increase their vulnerabilities to harms and wrongs”*. The complex nature of obtaining informed consent in diverse cultural and socioeconomic context, especially during public health emergencies is particularly difficult. Whilst these issues are under ethical debate, there is currently no definite consensus opinion, especially for children and young persons [8]. Children and, to a lesser extent, young persons lack the capacity to consent, therefore, the ethical consensus in adult research cannot be extrapolated to paediatrics. The Mental Capacity Act [9] applies to children who are 16 years and over. *“Mental capacity is present if a person can understand information given to them, retain the information given to them long enough to make a decision, can weigh up the advantages and disadvantages of the proposed course of treatment in order to make a decision, and can communicate their decision.”* [9, 10]. Once a young person is sixteen years old, they are deemed competent to consent or refuse treatment and their parents cannot override them. For children under sixteen years of age the Act does not apply and they need to be assessed for ‘Gillick competence’. This a term used in law to decide if a child is competent to consent for their own medical

treatment, without parental permission or knowledge. Parents cannot override a competent child’s refusal to accept treatment. Gillick competency is a professional assessment and there is no set of defined questions [11]. It is often used in a wider context to help assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions.

Prospective consent is the golden standard of consent. As children cannot legally consent, this is sought from parents or their legal guardian [8]. Obtaining assent from the child or young person (CYP) is deemed best clinical practice.

In 2008 the United Kingdom (UK) amended legislation allowing deferred consent for research in an emergency setting [12]. Collecting samples in an emergency allows increased access to quality samples (for example before treatments are given) but also allows samples to be taken at the same time as clinically necessary tests which reduces the number of potentially invasive or painful tests (blood sampling) and the distress that can cause for CYP.

Deferred consent addresses difficulties encountered whilst conducting research in emergency settings [13], mainly those related to time constraints for sample collection and parental capacity in a stressful setting [14, 15]. Others argue deferred consent interferes with core values of informed consent, represents a dishonest attempt to justify recruitment without consent, and compromises autonomy [14].

Further ethical issues involve re-consent. As children grow up, most children developmentally move from minimal to robust autonomy in adolescence, and develop the capacity to consent [16]. Biobanked samples might be stored and used for decades, by which time the CYP will have developed capacity, and may have new insights regarding use of their donated samples and associated personal data [4]. This suggests that re-consent may be necessary to justify use of the samples beyond childhood.

Although aforementioned ethical issues are under debate, the literature mainly focuses on the theoretical debate [4, 17, 18] or involves perspectives of parents or legal guardians [5, 19, 20], practitioners [15], the critically ill [14, 21] or adolescents already participating in research involving biobanks [22, 23]. Perspectives of the general population mainly involves adults, with university students being closest to the paediatric population [24, 25]. Literature on the CYP’s perspective is surprisingly sparse, despite being fundamental to the ongoing ethical debate.

This study aimed to assess CYP perspectives in the community towards prospective consent, deferred consent, re-consent and assent for biobanked samples. Secondary, we investigated views on sample donation, donation hesitation and data handling.

Methods

Study design and ethics

This was a cross-sectional, qualitative survey-based study. Anonymity of participants was maintained throughout the entire study. As part of the Diagnosis and Management of Febrile Illness using RNA Personalised Molecular Signature Diagnosis (DIAMONDS) study, ethics approval was obtained for the UK under: IRAS 209035, REC 16/LO/1684. DIAMONDS aims to establish a biobank of host gene signatures of common inflammatory and infectious causes of febrile disease in children. The survey was voluntary and anonymous. Informed consent was obtained from all participants. Written informed consent for the survey from parents or legal guardians was not required or obtained for patients under 16 years of age, with approval from the Newcastle and North Tyneside Research Ethics Committee. The survey was registered with our local audit registry, under audit number 13906.

Parental input was seen as a barrier to CYP participation and would potentially influence the responses. The co-produced element of the project ensured the subject and information created was CYP friendly, which significantly impacts their capacity to understand the circumstances and details of the research being proposed. The information was written and presented in a CYP friendly manner, to ensure CYP had all the information required to consent. Gillick competence was applied: reading the introductory information paragraph preceding the survey and the ability to complete the survey constituted consent for participants under the age of 16 years.

Participants

The target population were CYP attending secondary schools in the North East of England. Any CYP aged 11–21 years inclusive involved with the Young Person's Advisory Group North England (YPAGne) was invited to complete the survey, and they recruited further CYP who were not YPAGne members from their respective secondary schools. The participants did not donate samples to the DIAMONDS study and they were specifically asked to look independently at the ethical implications of biobanking biospecimens.

Survey development

The tailored survey was designed by volunteer CYP co-opted from YPAGne together with experienced researchers. YPAGne (<https://sites.google.com/nih.ac.uk/ypagne>) is an independent organisation within our hospital that exists to promote youth voice in health research and involve them in a variety of research projects from conception until the end. The co-opted CYP

who designed the survey voluntarily chose to work on the biobanking project out of their own interest. The Youth Collective Engagement Coordinator (JBa), who is not medically trained, facilitates the projects, ensures impartiality and aims to maximise the CYP's skill development through research projects. The DIAMONDS team approached YPAGne to conduct this survey project on CYP perspectives regarding biobanking.

The CYP undertook a literature review and met with independent researchers with extensive biobanking knowledge to gain more knowledge on the topic of biobanking.

Subsequently the co-opted CYP developed the hypothetical case scenarios and the survey questions, in multiple sessions. At this stage researchers in the DIAMONDS consortium were not yet involved, to ensure survey development was neutral and not affected by any potential bias induced by the research team.

A pilot was conducted, within the wider YPAGne forum, to provide feedback on the suitability and clarity of the survey. In a facilitated group session, minor semantic modifications were made in consultation with the DIAMONDS research team, and the final version of the survey approved. There were no major modifications on the content of the survey, as the research team was in agreement with the proposed survey. After some debate, a paragraph explaining what the purpose of biobank is, was added to the survey. This was felt necessary to ensure CYP in the community with no prior knowledge of biobanking could meaningfully complete the survey.

The final survey consisted of three sections, preceded by an introductory page explaining the purpose of the study, biobanking, anonymous and voluntary participation. Survey completion was regarded as agreement to participation and consent.

The first section covered demographic data. The second section included case-based questions regarding prospective consent, deferred consent, and re-consent and assent. The final section assessed attitudes towards sample donation and data confidentiality.

Data collection

The final survey (Additional File 1) was created using Google Forms (<http://docs.google.com/forms/>). The weblinks for the survey were distributed by CYP via their schools' email service, YPAGne's Facebook page, and other social media platforms such as WhatsApp, Instagram, Twitter and Snapchat. Data was collected from February to April 2021, with a second survey distribution in December 2021 to achieve data saturation.

Measures

Demographics

Participants were asked their age (in groups), self-identified gender (male, female, prefer not to say, other), partial postcodes, previous knowledge of biobanking (yes/no), and any previous hospital admission (yes/no).

Case-based consent procedures for biobanking

Case 1 revolved around prospective informed consent. We presented a case of a CYP attending for routine medical procedures and being asked to donate an extra sample for a biobank. Case 2 involved deferred consent. We described a case in which CYP had blood taken for a diagnostic test in an emergency and an extra blood sample preserved for biobanking. Consent was asked retrospectively with an option for the sample to be destroyed if consent was not given. Attitudes regarding prospective and deferred consent were measured on a 4-point scale ranging from 'strongly disagree' to 'strongly agree'. Subsequently, participants were asked to explain their answer in an open-ended question.

In case 3, we explored when a parent or legal guardian consented to a CYP having a blood sample stored in a biobank for research, if the participant would want to be asked at a later age whether they would give permission for their sample to be biobanked. If they wanted this, we asked at what age, and their opinions on re-consent or assent.

Lastly, we asked if the participant felt that CYP should be involved in the consent procedure whenever possible, and why.

Sample donation and data handling

We asked what kind(s) of biospecimens participants would be comfortable with donating to a biobank if they were collected for medical or surgical procedures regardless, followed by a question about why they would not be comfortable donating any samples. We also asked participants what information they would feel comfortable with to be stored alongside their biobanked specimens, and why they might be hesitant to donate samples to a biobank. To conclude the survey, they were asked about preferences regarding being informed when their sample is used, how they want to find out and what they want to know about sample use.

Data analysis

Quantitative data from closed questions were analysed in SPSS version 27 [Armonk USA 2020].

Qualitative data from open-ended questions were analysed using a qualitative thematic approach. Three reviewers independently analysed the open questions.

The first group of reviewers consisted of two CYP working on our study (LG and JBr) with the assistance of an experienced researcher (LH). In separate meetings they explored the data identified common themes. One meeting each was dedicated to prospective consent, deferred consent, re-consent, or donation hesitation and data confidentiality. The second (FvdV) and third (EL) reviewers identified common themes on these subjects independently. The fourth reviewer (JC) triangulated the analyses from the three reviewers to enable independent reporting and data saturation [26].

Results

One hundred two CYP completed the survey. The majority of participants were female (66.7%, $N=68$), from North East England and Cumbria (86.2%, $N=88$), between 16–18 years old (63.7%, $N=65$), and had no previous knowledge of biobanking (72.3%, $N=74$). Table 1 shows the demographic characteristics of the participants, and Table 2 gives an overview of quotes from participants on the different consent approaches.

Prospective consent

Most participants 91.2% ($N=93$) had a positive attitude towards prospective consent for biobanking: 46 agreed and 47 strongly agreed. Of the 9 participants with

Table 1 Demographic characteristics of CYP in survey ($N=102$)

Characteristic	N (%)
Gender (self-identified)	
Female	68 (66.7%)
Male	26 (25.5%)
Non-binary	1 (1.0%)
Agender	1 (1.0%)
Prefer not to say	6 (5.8%)
Age	
11 years	1 (1.0%)
12–15 years	13 (12.8%)
16–18 years	65 (63.7%)
≥ 18 years	23 (22.5%)
Geographical region	
North East England and Cumbria	88 (86.2%)
Greater London	11 (10.8%)
South West England	3 (3.0%)
Previous knowledge of biobanking	
Yes	28 (27.5%)
No	74 (72.5%)
Previous admission to hospital (overnight)	
Yes	41 (40.2%)
No	61 (59.8%)

Table 2 Illustrative CYP quotes by consent strategy for biobanking and identified common themes

Consent strategy	Quote
Prospective consent	
Altruism	<i>'Medical research is very important, and I would not mind helping' 'It allows the NHS to help more people who need it more than me'</i>
Benefits outweigh risks	<i>'There is no difference having extra taken, when the good it can do is immense' 'I have been asked for consent, and the procedure is happening anyways, so no harm to take it'</i>
Frugality	<i>'It would be a shame for any blood or tissue to go to waste when it could help someone'</i>
(In)convenience	<i>'It depends on what they're taking and if I feel comfortable with it' 'It might depend on whether it would have noticeable impact on me/recovery time'</i>
Deferred consent	
Altruism	<i>'Happy [to donate] if there is something left that could be helpful' 'It has no effect on me, yet has benefits for other people'</i>
Body integrity	<i>'I'm not entirely sure on this one: as long as consent is asked after it should be okay, but I also don't like the idea of something being done to my body without consent in advance' 'I think deferred consent is wrong and I would definitely feel violated in this case'</i>
Frugality	<i>'I think destroying the sample would be a waste so it should go to a biobank' 'If the blood had been taken, it would better be used for something, rather than just being destroyed'</i>
Assent and Reconsent	
Ownership	<i>'I think children deserve the right to consent, as long as they understand the choice they are making' 'A child's no should be able to override a parents' yes. But a child's yes should require a yes from the parents as well' 'I think parents should make most of the decisions for young children, but definitely talk to them about it and ask how they feel'</i>

negative attitudes (8.8%), only 1 strongly disagreed with prospective consent to biobanking.

Altruistic reasons for participation were frequently expressed in statements such as: *"I think the research done on it will be good for future patients"* and *"To take [from the health care system] you should be willing to give"*.

Participants indicate potential benefits of specimen donation, outweigh the risk of the additional procedure. *"I would feel happy about giving an extra blood sample. I would agree to a tissue sample if it would not leave side effects or much extra scarring"*.

They did voice important considerations and would not necessarily agree to donating without clear communication. Participants want to know how and what the sample is used for: *"I would be content as long as it goes to a good cause"* or *"I'd be happy with additional samples to be taken as extra to the procedure being done given an informative explanation"*. They also highlighted the importance of being given information in advance, stating *"I would be fine with it, but would require a bit of time beforehand; just so I am fully aware of what I'm doing"*.

The most common reasons for those less positive about biobanking were: needle phobia, perceived additional pain related to the procedure or concerns about how the sample will be used.

Deferred consent

Deferred consent was highly acceptable among participants (84.3%): 18 agreed, and 68 strongly agreed. Only five strongly disagreed with deferred consent for biobanking (4.9%).

We observed a shift in motivation with less of a focus on altruism, but more towards frugality (Table 1). Participants realise and accept, in emergency situations, samples may be taken prior to consent being obtained. The majority of participants stated opinions such as *"They would not use my sample for anything until I had given consent, so the choice is still in the hands of the patient"* and *"I really don't mind. If it's an emergency situation it's clearly inappropriate to ask at the time, so asking afterwards is fine. Again, as long as it has no effect on my care, take what you need"*. Others feel more uncomfortable but would still agree: *"I would be quite annoyed if they [take a sample for biobanking] without consent, but I'd also be happy for it to be used"*. A few disagreed with the concept and one person stated how this impacted their autonomy and dignity: *"I think deferred consent is wrong and I would definitely feel violated in this case"*.

In cases where consent is refused, participants described the importance of trust and transparency regarding sample handling. *"I think it is important to provide reassurance and information about how the sample will be destroyed to ensure patients who did not give consent do not need to worry about the hospital keeping the sample"*.

Assent and reconsent

All participants thought CYP should be involved in the consent procedure, *"Children still have rights and I think it's important that they feel included in decisions about their own body and medical care"*. Participants thought CYP

should have the ‘power of veto’ over donating samples “A child’s no should be able to override a parents yes. But a child’s yes should require a yes from the parents as well”.

Three quarters of participants (76.5%, N=78) wanted to be contacted at an older age to reconsent for sample use, if they had samples taken before the age of capacity but a quarter (24.5%, N=25) did not feel they needed to be contacted again. With regards to age of reconsent, 61 participants (59.8%) stated an age range of 16–18 years to be appropriate, in line with legal age of consent “I would say when you reach an age where you can make your own medical decisions whilst understanding the consequences, 16–18.” However, there was a wide range of suggested ages from 7 to 21 years.

Sample donation and data handling

Almost all participants were comfortable donating blood (97.1%, N=99) and urine (89.2%, N=91) (Fig. 1). Participants felt the main reasons CYP might hesitate to donate samples were privacy (55.6%, N=40/72) “People might worry about their personal data being lost or stolen.”, personal views (37.5%, N=27/72) e.g. “[I] don’t like the idea of my tissue being kept and used for long period of time and not knowing what it is used for” and embarrassment “Donating faeces can make many people feel uncomfortable” and ethical views (23.6%, N=17/72): “I would only donate samples if I knew exactly how they would be used, in line with my own personal views.”

If CYP donate biospecimens to a biobank, the majority of participants agree that medical details could be stored alongside the sample (82.2%, N=83). They acknowledge that their donated samples were more valuable when linked to additional clinical data, “The information will help make the sample more useful so I would be happy providing extra details”.

The minority who had reservations about additional information being stored, would be satisfied if data is stored without personal identifiers. “There should be absolutely no identifying information, or any information

that is not strictly related to you [sic] biological medical record” and “as long as the government doesn’t make blood-tracing nanobots that could find me, then I’m fine.”

One-fifth of participants are not interested in following their samples “[I] don’t really mind what the clever clogs do with it”. The majority of participants (81.2%, N=81) would like to know more about how their samples are used but are pragmatic in their requests, “It would be interesting to know but if it is more work/expenses for hospitals etc. I don’t mind not knowing” suggesting the “Ability to opt in to receiving updates on research”.

Discussion

This study provides insights from UK CYP on consent procedures and ethical issues surrounding participation in research involving biobanks. It adds valuable data in a field where there is little literature on CYP perspectives.

In our surveyed population we demonstrate CYP have positive attitudes towards participation in research involving biobanks, and acceptability of both prospective and deferred consent is high. Altruism, sample frugality and bodily integrity were important themes for CYP, concurrent with views of adults [23, 24], and CYP participating in critical care trials [21]. We acknowledge that there is hesitancy in a minority of CYP to donate, due to needle phobia, pain, or aversion towards the bodily fluid to be donated. While we expected needle phobia and pain to be main barriers to donation, we were surprised by the young people’s hesitancy to donate stool samples, due to perceived embarrassment.

In line with previous studies involving the views of practitioners [15] and parents [14], CYP were receptive to deferred consent, provided it was obtained appropriately [15]. This is a marked change, compared to a similar small unpublished survey conducted in our centre previously, in which CYP from the same region were less receptive to deferred consent. Post-hoc, we identified two potential factors may have influenced this, although these were not specifically mentioned by the participants.

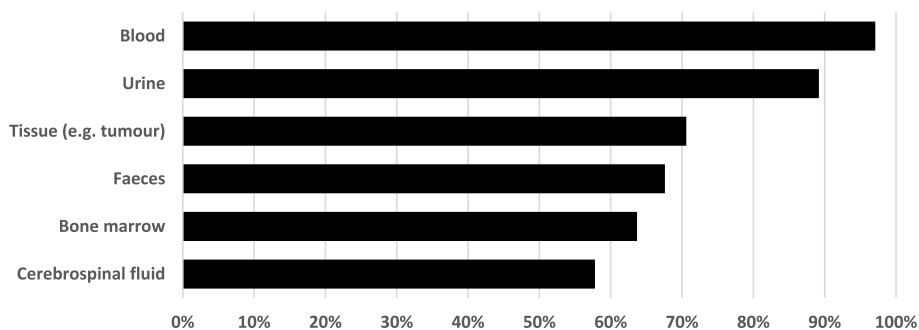


Fig. 1 Acceptability (%) for sample donation by sample type

First, the coronavirus disease 2019 (COVID-19) pandemic. The pandemic introduced viral testing on a large scale to the general population, including CYP. During this time, media outlets frequently reported on the scientific progress made into this novel disease, utilizing data generated from COVID-19 swabs taken from the general public. This introduced CYP to a surrogate process of donating biospecimens to biobanks for research and what impact this contribution might have. Having experienced donating biospecimens, attitudes to aforementioned factors might have changed.

Second, in 2020, the new organ donation law in England came into effect, changing the opt-in to an opt-out system [27]. The opt-out system can effectively be seen as a proxy deferred consent, as it assumes every adult is happy to be an organ donor, unless they actively record a decision to be excluded from the donor programme. We postulated that this may have raised awareness of different forms of consent practices nationally. Deferred consent for biobanking assumes consent to take biospecimens with a retrospective option to decline for the sample to be used. The reasoning behind this option is to reduce the number of sample attempts (i.e. blood draws) to minimise pain and distress in children and young people.

The right to assent is protected by the United Nations Convention on the Rights of the Child, article 12, which states: “States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” [28]. Our results clearly show that CYP should be actively involved in the consent procedure, by giving assent in conjunction with their parents, or by being approached for re-consent once they are old enough. Some participants provided accounts of negative personal experiences in hospital and not being involved or listened to, in order to emphasize the importance of CYP participation in their own healthcare and maintaining autonomy. The benefit and need for CYP with capacity to assent has become increasingly clear [29–33]. This is consistent with the attitude that children have grown more independent within the home, school, and medical setting [34], and increasingly seen as autonomous individuals [35]. There are concerns that CYP might lack capacity to give meaningful consent particularly around the complex concept of biobanking [21, 36]. However, there is evidence that even adults lack a deeper understanding of biobanking [23]. McGregor and Ott [37] demonstrated the capacity of adolescents/young adults (aged 12–24 years) to consent is similar to that of adults. Therefore, aiding CYP to provide meaningful informed consent is a pivotal task of the

consenting researcher, and should be achievable in most circumstances.

CYP are largely supportive of having medical data stored alongside their biobanked sample and recognized the value of data and risks of data sharing. Due to widespread social media use, CYP are used to providing consent and understanding their risks and benefits of sharing their personal data. CYP with long-term conditions using health technology to manage their illness [38] have highlighted such concerns. Concerns about governance and entrusting their sample to a biobank are legitimate in light of the Alder Hey organ scandal, involving the removal of human tissue and organs of hundreds of deceased children without the knowledge and consent of their parents between 1988 and 1996. Following public inquiry [39], this led to the Human Tissue Act 2004 [40] and new recommendations for consent approaches, to prevent this from happening again [41].

Research requires trust from those willing to participate. It is vital CYP are provided with sufficient, comprehensive information tailored to their age and expected level of understanding. It is important that clear and transparent information on privacy, data and sample handling is available and clearly communicated.

Limitations

Although this study adds to the paucity of community CYP perspectives on consent procedures and ethical issues surrounding biobanking, it has limitations. Most respondents were from the North East of England, and their views might not represent those in the UK as a whole. This study was conducted in a high-income country, and there is currently no evidence to support whether our results might be applicable to low- or middle-income country settings or, other cultural settings. Specific ethical challenges have been reported surrounding the ethical adequacy for large-scale biobanking and sample use during disease outbreaks, for example during the 2014 Ebola outbreak in Africa [42], that are rarely seen in the setting of high-income countries.

Additionally, we acknowledge that most of our participants are older and female CYP, and the perspectives could change if we had a larger proportion of younger CYP. The current number of younger participants was too low to conduct a subset analysis.

The survey allowed for opinions and perspectives to be shared by the participants, but our data lacks the in-depth detail you could get from an interview-based approach.

Conclusions

For CYP in the UK prospective and deferred consent are highly acceptable in the context of biobanking.

CYP should be included in consent procedures for biobank participation, when they reach capacity.

Important themes surrounding consent are altruism, frugality, body integrity and ownership.

Clear communication and justification of the need for biobanking is paramount to ensure willingness to participate in research involving biobanking.

This study highlights the lack of clear guidelines and information around consent procedures for biobanking of samples from children and young persons. We would suggest that national bodies need to develop these in conjunction with active engagement and input from CYP themselves.

Abbreviations

CYP	Children and young people
DIAMONDS	Diagnosis and Management of Febrile Illness using RNA Personalised Molecular Signature Diagnosis
UK	United Kingdom
YPAGne	Young Person's Advisory Group North England

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12910-023-00925-v>.

Additional file 1.

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DIAMONDS consortium

Michael Levin⁷, Aubrey Cunnington⁷, Jethro Herberg⁷, Myrsini Kaforou⁷, Victoria Wright⁷, Evangelos Bellos⁷, Claire Broderick⁷, Samuel Channon-Wellis⁷, Samantha Cooray⁷, Tisham De⁷, Giselle D'Souza⁷, Leire Estramiana Elorrieta⁷, Diego Estrada-Rivadeneira⁷, Rachel Galassini⁷, Dominic Habgood-Coote⁷, Shea Hamilton⁷, Heather Jackson⁷, James Kavanagh⁷, Mahdi Moradi Marjaneh⁷, Samuel Nichols⁷, Ruud Nijman⁷, Harsita Patel⁷, Ivana Pennisi⁷, Oliver Powell⁷, Ruth Reid⁷, Priyanshu Shah⁷, Ortensia Vito⁷, Elizabeth Whittaker⁷, Clare Wilson⁷, Rebecca Womersley⁷, Amina Abdulla⁸, Sarah Darnell⁸, Sobia Mustafa⁸, Pantelis Georgiou⁹, Jesus-Rodriguez Manzano¹⁰, Nicolas Moser⁹, Michael Carter¹¹, Shane Tibby¹¹, Jonathan Cohen¹¹, Francesca Davis¹¹, Julia Kenny¹¹, Paul Wellman¹¹, Marie White¹¹, Matthew Fish¹², Aislinn Jennings¹³, Manu Shankar-Hari¹³, Katy Fidler¹⁴, Dan Agranoff¹⁵, Julia Dudley¹⁴, Vivien Richmond¹⁴, Matthew Seal¹⁵, Saul Faust¹⁶, Dan Owen¹⁶, Ruth Ensom¹⁶, Sarah McKay¹⁶, Diana Mondo¹⁷, Mariya Shaji¹⁷, Rachel Schranz¹⁷, Prita Rughnani¹⁸, Amutha Anpananhar¹⁹, Susan Liebeschuetz²⁰, Anna Riddell¹⁸, Divya Divakaran¹⁹, Louise Han¹⁹, Noshreen Khalid¹⁸, Ivone Lancoma Malcolm¹⁹, Jessica Schofield¹⁹, Teresa Simagan¹⁹, Mark Peters²¹, Alasdair Bamford²¹, Laurant O'Neill²¹, Nazima Pathan²², Esther Daubney²³, Debora White²³, Melissa Heightman²⁴, Sarah Eisen²⁴, Terry Segal²⁴, Lucy Wellings²⁴, Simon B Drysdale²⁵, Nicole Branch²⁵, Lisa Hamzah²⁵, Heather Jarman²⁵, Maggie Nyirenda²⁵, Lisa Capozzi²⁶, Emma Gardiner²⁶, Robert Moots²⁷, Magda Nasher²⁸, Anita Hanson²⁸, Michelle Linforth²⁷, Sean O'Riordan²⁹, Donna Ellis²⁹, Akash Deep³⁰, Ivan Caro³⁰, Fiona Shackley³¹, Arianna Bellini³¹, Stuart Gormley³¹, Samira Neshat³², Barnaby J Scholefield³³, Ceri Robbins³³, Helen Winmill³³, Stéphane C Paulus³⁴, Andrew J Pollard³⁵, Mark Anthony³⁶, Sarah Hopton³⁶, Danielle Miller³⁶, Zoe Oliver³⁶, Sally Beer³⁶, Bryony Ward³⁶, Shrijana Shrestha³⁷, Meeru Gurung³⁷, Puja Amaty³⁷, Bishma Pokhrel³⁷, Sanjeev Man Bujukchhe³⁷, Madhav Chandra Gautam³⁷, Peter O'Reilly³⁵, Sonu Shrestha³⁵, Federico Martinón-Torres³⁸, Antonio Salas³⁸, Fernando Alvez González³⁸, Sonia Ares Gómez³⁸, Xabier Bello³⁸, Miriam Ben García³⁸, Fernando Caamaño Viña³⁸, Sandra Carnota³⁸, María José Curras-Tuala³⁸, Ana Dacosta Urbiet³⁸, Carlos Durán Suárez³⁸, Isabel Ferreiros Vidal³⁸,

Luisa García Vicente³⁸, Alberto Gómez-Carballea³⁸, Jose Gómez Rial³⁸, Pilar Leboráns Iglesias³⁸, Narmeen Mallah³⁸, Nazareth Martinón-Torres³⁸, José María Martínón Sánchez³⁸, Belén Mosquera Perez³⁸, Jacobo Pardo-Seco³⁸, Sara Pischedda³⁸, Sara Rey Vázquez³⁸, Irene Rivero Calle³⁸, Carmen Rodríguez-Tenreiro³⁸, Lorenzo Redondo-Collazo³⁸, Sonia Serén Fernández³⁸, Marisol Vilas Iglesias³⁸, Enital D Carro³⁹, Elizabeth Cocklin³⁹, Abbey Bracken³⁹, Ceri Evans⁴⁰, Aakash Khanijau³⁹, Rebecca Lenihan³⁹, Nadia Lewis-Burke³⁹, Karen Newall⁴¹, Sam Romaine³⁹, Jennifer Whitbread³⁹, Maria Tsolia⁴², Irini Eleftheriou⁴², Nikos Spyridis⁴², Maria Tambouratzi⁴², Despoina Maritsi⁴², Antonios Marmarinos⁴², Marietta Xagorari⁴², Lourida Panagiota⁴³, Pefanis Aggelos⁴³, Akinosoglou Karolina⁴⁴, Gogos Charalambos⁴⁴, Maragos Markos⁴⁴, Voulgarelis Michalis⁴⁵, Stergiou Ioanna⁴⁵, Marieke Emonts^{1,2}, Emma Lim^{1,5,6}, John Isaacs², Kathryn Bell⁴⁶, Stephen Crulley⁴⁶, Daniel Fabian⁴⁶, Evelyn Thomson⁴⁶, Diane Walia⁴⁶, Caroline Miller⁴⁶, Ashley Bell⁴⁶, Fabian JS van der Velden^{1,2}, Geoff Shenton⁴⁷, Ashley Price⁴⁸, Owen Treloar², Daisy Thomas¹, Pablo Rojo⁴⁹, Cristina Epalza⁴⁹, Serena Villaverde⁴⁹, Sonia Márquez⁴⁹, Manuel Gijón⁴⁹, Fátima Marchán⁴⁹, Laura Cabello⁴⁹, Irene Hernández⁴⁹, Lourdes Gutiérrez⁴⁹, Ángela Manzanares⁴⁹, Taco W Kuijpers⁵⁰, Martijn van de Kuip⁵⁰, Marceline van Furth⁵⁰, Merlijn van den Berg⁵⁰, Giske Biesbroek⁵⁰, Floris Verkuil⁵⁰, Carlijn W van der Zee⁵⁰, Dasja Pajkr⁵⁰, Michael Boele van Hensbroek⁵⁰, Dieneke Schonenberg⁵⁰, Mariken Gruppen⁵⁰, Sietse Nagelkerke⁵⁰, Machiel H Jansen⁵⁰, Ines Goedschalck⁵¹, Lorenza Romani⁵², Maia De Luca⁵², Sara Chiurchiù⁵², Constanza Tripiciano⁵², Stefania Mercadante⁵², Clementien L Vermont⁵³, Henriëtte A Mol⁵⁴, Dorine M Borensztajn⁵⁴, Nienke N Hagedoorn⁵⁴, Chantal Tan⁵⁴, Joany Zachariasse⁵⁴, Willem A Dik⁵⁵, Shen Ching-Fen⁵⁶, Dace Zavadska⁵⁷, Sniedze Laivacuma⁵⁸, Aleksandra Rudzate⁵⁷, Diana Stoldere⁵⁷, Arta Barzdina⁵⁷, Elza Barzdina⁵⁷, Monta Madelane⁵⁹, Dagne Gravele⁵⁹, Dace Svile⁵⁹, Romain Basmaci⁶⁰, Noémie Lachaume⁶⁰, Pauline Bories⁶⁰, Raja Ben Tkhayat⁶⁰, Laura Chériaux⁶⁰, Jurat Davoust⁶⁰, Kim-Thanh Ong⁶⁰, Marie Cotillon⁶⁰, Thibault de Groc⁶⁰, Sébastien Le⁶⁰, Nathalie Vergnault⁶⁰, Hélène Sée⁶⁰, Laure Cohen⁶⁰, Alice de Tugny⁶⁰, Nevena Danekova⁶⁰, Marine Mommert-Tripon⁶¹, Marko Pokorn⁶², Mojca Kolnik⁶², Tadej Avčin⁶², Tanja Avramoska⁶², Natalija Bahovec⁶³, Petra Bogovič⁶³, Lidija Kitanovski⁶², Mirjam Nahtigal⁶³, Lea Papst⁶³, Tina Plankar Srovin⁶³, Franc Strle⁶³, Katarina Vincek⁶³, Michiel van der Flier⁶⁴, Wim JE Tissing⁶⁵, Roelie M Wösten-van Asperen⁶⁶, Sebastiaan J Vastert⁶⁷, Daniel C Vijlbrief⁶⁸, Louis J Bont⁶⁹, Tom FW Wolfs⁶⁹, Coco R Beudeker⁶⁹, Sanne C Hulsman⁶⁹, Philipp KA Agyeman⁷⁰, Luregn Schlapbach⁷¹, Christoph Aebi⁷⁰, Mariama Usman⁷⁰, Stefanie Schlüchter⁷⁰, Verena Wyss⁷⁰, Nina Schöbi⁷⁰, Elisa Zimmermann⁷⁰, Marion Meier⁷¹, Kathrin Weber⁷¹, Eric Giannoni⁷², Martin Stocker⁷³, Klara M Posfay-Barbe⁷⁴, Ulrich Heininger⁷⁵, Sara Bernhard-Stirmemann⁷⁶, Anita Niederer-Loher⁷⁷, Christian Kahlert⁷⁸, Giancarlo Natalucci⁷⁹, Christa Relly⁸⁰, Thomas Riedel⁸¹, Christoph Berger⁸¹, Colin Fink⁸², Marie Voice⁸², Leo Calvo-Bado⁸², Michael Steele⁸², Jennifer Holden⁸², Andrew Taylor⁸², Roman Calvez⁸², Catherine Davies⁸², Benjamin Evans⁸², Jake Stevens⁸², Peter Matthews⁸², Kyle Billing⁸², Werner Zenz⁸³, Alexander Binder⁸³, Benno Kohlmaier⁸³, Daniel S Kohlfürst⁸³, Nina A Schweitzger⁸³, Christoph Zurl⁸³, Susanne Hösel⁸³, Manuel Leitner⁸³, Lena Pölz⁸³, Alexandra Rusu⁸³, Glorija Rajic⁸³, Bianca Stoiser⁸³, Martina Strempl⁸³, Manfred G Sagneister⁸³, Sebastian Bauchinger⁸³, Martin Benesch⁸⁴, Astrid Ceolotto⁸³, Ernst Eber⁸³, Siegfried Gallist⁸³, Harald Haid⁸³, Almuthe Hauer⁸³, Christa Hude⁸³, Andreas Kapper⁸⁵, Markus Keldorfer⁸⁶, Sabine Löffler⁸⁶, Tobias Niedrist⁸⁷, Heidemarie Pilch⁸⁶, Andreas Pflieger⁸⁸, Klaus Pfurtscheller⁸⁹, Siegfried Rödl⁸⁹, Andrea Skrabl-Baumgartner⁸³, Volker Strenger⁸⁴, Elmar Wallner⁸⁵, Maike K Tauchert⁹⁰, Ulrich von Both⁹¹, Laura Kolberg⁹¹, Patricia Schmid⁹¹, Ioanna Mavridi⁹¹, Irene Alba-Alejandre⁹², Katharina Danhauser⁹³, Niklaus Haas⁹⁴, Florian Hoffmann⁹⁵, Matthias Griese⁹⁶, Tobias Feuchtinger⁹⁷, Sabrina Juranek⁹⁸, Matthias Kappler⁹⁶, Eberhard Lurz⁹⁹, Esther Maier⁹⁸, Karl Reiter⁹⁵, Carola Schoen⁹⁵, Sebastian Schroepl¹⁰⁰, Shunmay Yeung¹⁰¹, Manuel Dewez¹⁰¹, David Bath¹⁰², Elizabeth Fitchett¹⁰¹, Fiona Cresswell¹⁰¹, Effua Usuf¹⁰³, Kalifa Bojang¹⁰³, Anna Roca¹⁰³, Isatou Sarr¹⁰³, Momodou Ndure¹⁰³

⁸Children's Clinical Research Unit, St Mary's Hospital, Praed Street, London W2 1NY, UK

⁹Imperial College London, Department of Electrical and Electronic Engineering, South Kensington Campus, London, SW7 2AZ, UK

¹⁰Imperial College London, Department of Infectious Disease, Section of Adult Infectious Disease, Hammersmith Campus, London, W12 0NN, UK

¹¹Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust, London, UK

¹²Department of Infectious Diseases, School of Immunology and Microbial Sciences, King's College London, London, UK

¹³Department of Intensive Care Medicine, Guy's and St Thomas' NHS Foundation Trust, London, UK

- ¹⁴Royal Alexandra Children's Hospital, University Hospitals Sussex, Brighton, UK
- ¹⁵Dept of Infectious Diseases, University Hospitals Sussex, Brighton, UK
- ¹⁶NIHR Southampton Clinical Research Facility, University Hospital Southampton NHS Foundation Trust and University of Southampton, UK
- ¹⁷Department of R&D, University Hospital Southampton NHS Foundation Trust, UK
- ¹⁸Royal London Hospital, Whitechapel Rd, London E1 1FR, UK
- ¹⁹Whipps Cross University Hospital, Whipps Cross Road, London, E11 1NR, UK
- ²⁰Newham University Hospital, Glen Rd, London E13 8SL, UK
- ²¹Great Ormond Street Hospital, London, WC1N 3JH, UK
- ²²Department of Paediatrics, University of Cambridge, Cambridge CB2 0QQ, UK
- ²³Addenbrooke's Hospital, Hills Road, Cambridge CB2 0QQ, UK
- ²⁴University College London Hospital, Euston Road, London NW1 2BU, UK
- ²⁵St George's Hospital, Blackshaw Road, London SW17 0QT, UK
- ²⁶University Hospital Lewisham, London SE13 6LH, UK
- ²⁷Aintree University Hospital, Lower Lane, Liverpool L9 7AL, UK
- ²⁸Royal Liverpool Hospital, Prescot St, Liverpool L7 8XP, UK
- ²⁹Leeds Children's Hospital, Leeds LS1 3EX, UK
- ³⁰Kings College Hospital, Denmark Hill, London SE5 9RS, UK
- ³¹Sheffield Children's Hospital, Broomhall, Sheffield S10 2TH, UK
- ³²Leicester General Hospital, Leicester LE1 5WW, UK
- ³³Birmingham Children's Hospital, Steelhouse Lane, Birmingham B4 6NH, UK
- ³⁴Department of Paediatrics, University of Oxford, UK
- ³⁵Oxford Vaccine Group, University of Oxford, UK
- ³⁶John Radcliffe Hospital, Oxford University Hospitals NHS Foundation Trust, Oxford, UK
- ³⁷Paediatric Research Unit, Patan Academy of Health Sciences, Kathmandu, Nepal
- ³⁸Translational Pediatrics and Infectious Diseases, Pediatrics Department, Hospital Clínico Universitario de Santiago, Santiago de Compostela, Spain
- ³⁹Institute of Infection, Veterinary and Ecological Sciences, University of Liverpool, Liverpool, UK
- ⁴⁰Alder Hey Children's Hospital, Department of Infectious Diseases, Eaton Road, Liverpool, L12 2AP, UK
- ⁴¹Alder Hey Children's Hospital, Clinical Research Business Unit, Eaton Road, Liverpool, L12 2AP, UK
- ⁴²2nd Department of Pediatrics, National and Kapodistrian University of Athens (NKUA), Children's Hospital "P. and A. Kyriakou", Athens, Greece
- ⁴³1st Department of Infectious Diseases, General Hospital "Sotiria", Athens, Greece
- ⁴⁴Pathology Department, University of Patras, General Hospital "Panagia i Voithia", Greece
- ⁴⁵Pathophysiology Department, Medical Faculty, National and Kapodistrian University of Athens (NKUA), General Hospital "Laiko", Athens, Greece
- ⁴⁶Great North Children's Hospital, Paediatric Research Team, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, United Kingdom
- ⁴⁷Great North Children's Hospital, Paediatric Oncology, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, United Kingdom
- ⁴⁸Department of Infection & Tropical Medicine, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, United Kingdom
- ⁴⁹Servicio Madrileño de Salud, Pediatric Infectious Diseases Unit, Department of Pediatrics, Hospital Universitario 12 de Octubre, Madrid, Spain
- ⁵⁰Amsterdam UMC, Emma Children's Hospital, Dept of Pediatric Immunology, Rheumatology and Infectious Disease, University of Amsterdam, The Netherlands
- ⁵¹Sanquin, Dept of Molecular Hematology, University Medical Center, Amsterdam, The Netherlands
- ⁵²Infectious Disease Unit, Academic Department of Pediatrics, Bambino Gesù Children's Hospital, IRCCS, Rome 00165, Italy
- ⁵³Erasmus MC-Sophia Children's Hospital, Department of Paediatric Infectious Diseases & Immunology, Rotterdam, the Netherlands
- ⁵⁴Erasmus MC-Sophia Children's Hospital, Department of General Paediatrics, Rotterdam, the Netherlands
- ⁵⁵Erasmus MC, Department of Immunology, Rotterdam, the Netherlands
- ⁵⁶Department of Pediatrics, National Cheng Kung University Hospital, College of Medicine, National Cheng Kung University, Tainan, Taiwan
- ⁵⁷Children's Clinical University Hospital, Riga Stradins University, Riga, Latvia
- ⁵⁸Riga East Clinical Hospital, Riga Stradins University, Riga, Latvia
- ⁵⁹Children's Clinical University Hospital, Riga, Latvia
- ⁶⁰Service de Pédiatrie-Urgences, AP-HP, Hôpital Louis-Mourier, F-92700 Colombes, France
- ⁶¹bioMérieux—Open Innovation & Partnerships Department, Lyon, France
- ⁶²University Children's Hospital, University Medical Centre Ljubljana, Slovenia
- ⁶³Department of Infectious diseases, University Medical Centre Ljubljana, Slovenia
- ⁶⁴Pediatric Infectious Diseases, Wilhelmina Children's Hospital, University Medical Center Utrecht, Utrecht, the Netherlands
- ⁶⁵Princess Maxima Center for Pediatric Oncology, Utrecht, the Netherlands
- ⁶⁶Pediatric Intensive Care Unit, University Medical Center Utrecht, Utrecht, the Netherlands
- ⁶⁷Pediatric Rheumatology, University Medical Center Utrecht, Utrecht, the Netherlands
- ⁶⁸Pediatric Neonatal Intensive Care, University Medical Center Utrecht, Utrecht, the Netherlands
- ⁶⁹Pediatric Infectious Disease and Immunology, University Medical Center Utrecht, Utrecht, the Netherlands
- ⁷⁰Department of Pediatrics, Inselspital, Bern University Hospital, University of Bern, Switzerland
- ⁷¹Department of Intensive Care and Neonatology, and Children's Research Center, University Children's Hospital Zurich, Zurich, Switzerland
- ⁷²Clinic of Neonatology, Department Mother-Woman-Child, Lausanne University Hospital and University of Lausanne, Switzerland
- ⁷³Department of Pediatrics, Children's Hospital Lucerne, Lucerne, Switzerland
- ⁷⁴Pediatric Infectious Diseases Unit, Children's Hospital of Geneva, University Hospitals of Geneva, Geneva, Switzerland
- ⁷⁵Infectious Diseases and Vaccinology, University of Basel Children's Hospital, Basel, Switzerland
- ⁷⁶Children's Hospital Aarau, Aarau, Switzerland
- ⁷⁷Division of Infectious Diseases and Hospital Epidemiology, Children's Hospital of Eastern Switzerland St. Gallen, St. Gallen, Switzerland
- ⁷⁸Department of Neonatology, University Hospital Zurich, Zurich, Switzerland
- ⁷⁹Division of Infectious Diseases and Hospital Epidemiology, and Children's Research Center, University Children's Hospital Zurich, Switzerland
- ⁸⁰Children's Hospital Chur, Chur, Switzerland
- ⁸¹Division of Infectious Diseases and Hospital Epidemiology, and Children's Research Center, University Children's Hospital Zurich, Switzerland
- ⁸²Micropathology Ltd, The Venture Center, University of Warwick Science Park, Sir William Lyons Road, Coventry, CV4 7EZ, UK
- ⁸³Department of Pediatrics and Adolescent Medicine, Division of General Pediatrics, Medical University of Graz, Graz, Austria
- ⁸⁴Department of Pediatric Hematooncology, Medical University of Graz, Graz, Austria
- ⁸⁵Department of Internal Medicine, State Hospital Graz II, Location West, Graz, Austria
- ⁸⁶University Clinic of Pediatrics and Adolescent Medicine Graz, Medical University Graz, Graz, Austria
- ⁸⁷Clinical Institute of Medical and Chemical Laboratory Diagnostics, Medical University Graz, Graz, Austria
- ⁸⁸Department of Pediatric Pulmonology, Medical University of Graz, Graz, Austria
- ⁸⁹Paediatric Intensive Care Unit, Medical University of Graz, Graz, Austria
- ⁹⁰Biobanking and BioMolecular Resources Research Infrastructure—European Research Infrastructure Consortium (BBMRI-ERIC), Neue Stiftingtalstrasse 2/B/6, 8010, Graz, Austria
- ⁹¹Division of Pediatric Infectious Diseases, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany
- ⁹²Department of Gynecology and Obstetrics, University Hospital, LMU Munich, Munich, Germany
- ⁹³Division of Pediatric Rheumatology, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany
- ⁹⁴Department of Pediatric Cardiology and Pediatric Intensive Care, University Hospital, LMU Munich, Germany
- ⁹⁵Paediatric Intensive Care Unit, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany
- ⁹⁶Division of Pediatric Pulmonology, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany
- ⁹⁷Division of Pediatric Haematology & Oncology, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany

⁹⁸Division of General Pediatrics, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany

⁹⁹Division of Pediatric Gastroenterology, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany

¹⁰⁰Neonatal Intensive Care Unit, Department of Pediatrics, Dr. von Hauner Children's Hospital, University Hospital, LMU Munich, Munich, Germany

¹⁰¹Clinical Research Department, Faculty of Infectious and Tropical Disease, London School of Hygiene and Tropical Medicine, London, UK

¹⁰²Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, London, UK

¹⁰³Medical Research Council at LSHTM, Fajara, the Gambia

Authors' contributions

EL, JBa, and ME conceptualized the project. LG, JBr, JBa, ER and EL designed the survey and collected the data. FvdV, LG, JBr, LH, JC, and EL analysed the data. JH and RG are responsible for the ethics within the DIAMONDS study. FvdV, EL and LG wrote the manuscript. All authors read, revised, and approved the final manuscript.

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Availability of data and materials

The datasets generated and analysed for this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This study is part of the DIAMONDS study and has ethics approval for the UK under: IRAS 209035, REC 16/LO/1684. This study was registered and had its protocols approved by the Newcastle upon Hospitals NHS Foundation Trust under local audit registry number 13906. This study and its methods were carried out in accordance with the Declaration of Helsinki and local NHS Trust policies. Participants were members of the community, and not clinical patients. Informed consent was obtained from all participants. Written informed consent for the survey from parents or legal guardians was not required or obtained for patients under 16 years of age, with approval from the Newcastle and North Tyneside Research Ethics Committee. Parental input was seen as a barrier to CYP participation and would potentially influence the responses. The co-produced element of the project ensured the subject and information created was CYP friendly, which significantly impacts their capacity to understand the circumstances and details of the research being proposed. The information was written and presented in a CYP friendly manner, to ensure CYP had all the information required to consent. Gillick competence was applied: reading the introductory information paragraph preceding the survey and the ability to complete the survey constituted consent for participants under the age of 16 years.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details

¹Paediatric Immunology, Infectious Diseases & Allergy, Great North Children's Hospital, The Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, UK. ²Translational and Clinical Research Institute, Newcastle University, Newcastle Upon Tyne, UK. ³Population Health Sciences Institute, Newcastle University, Newcastle Upon Tyne, UK. ⁴General Paediatrics, Great North Children's Hospital, The Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, UK. ⁵Young Person's Advisory Group North England, Great North Children's Hospital, The Newcastle Upon Tyne Hospitals

NHS Foundation Trust, Newcastle Upon Tyne, UK. ⁶The Great North Youth Forum, Great North Children's Hospital, The Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, UK. ⁷Section of Paediatric Infectious Disease, Wright-Fleming Institute, Imperial College London, London, UK.

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