NIHR | National Institute for Health and Care Research

Making Connections:
Children and Young People's Involvement in Research

CONTENTS

GenerationR

On Saturday, February 1st, 2025, 51 young people from 10 different groups across England came together for the Making Connections event in Birmingham. The event was organised by a team of 7 young people in collaboration with the GenerationR Alliance (based in Liverpool), the National Institute of Health and Care Research (NIHR) Research Delivery Network and funded by the the Department of Health and Social Care.

The agenda focused on:

- Supporting the emotional well-being of children and young people involved in health and social care (HSC) research
- Understanding what meaningful involvement in HSC research means to children and young people
- Identifying the skills, knowledge, and values children and young people want to see in HSC research staff

Following the event, a second webinar was held to share the findings with staff working in HSC research.

This report shares important views from children and young people who attended the event, the outcomes from the sessions and a summary of the planned next steps. Sharing of the findings with influential stakeholders and decision-makers will help to support deeper involvement and engagement, ensuring CYP continue to have a voice in HSC research.

1. BACKGROUND

1.a. Why now?

On the 11th September 2013, the NIHR Medicines for Children Research Network (MCRN) hosted an event to promote the involvement of children and young people (CYP), and their families in health research. The event named GenerationR (R for Research) by CYP themselves, was designed to showcase how CYP and families have contributed to improving the design, development and delivery of paediatric health research. It reflected their strong belief that meaningful involvement leads to higher-quality research, more effective implementation, and greater overall impact.

Now, more than 10 years on, NIHR and GenerationR, together with partner organisations, wanted to celebrate the progress made in involving CYP in HSC research. The event entitled 'Making Connections' hoped to serve as a moment to reflect on both the past and the future, celebrating progress made, but also exploring how to further embed and sustain CYP voices in HSC research awareness and decision-making.

At the heart of the event was a desire to demonstrate a strong commitment to upholding the rights of CYP; to be heard and represented in HSC. The United Nations Convention on the Rights of the Child (1989) affirms that 'every child and young person has the right to be heard when adults make decisions which affect their lives' (Article 12). Therefore there was a question to be explored around "how can we build effective mechanisms and platforms to enable genuine and sustainable collaborations with CYP? How can we empower them to co-design and co-produce both our research and how we involve them in shaping HSC research decisions?"

Four key objectives were identified to guide the planning of the event;

- To celebrate and highlight the progress and impact of the recommendations outlined in the GenerationR report since 2013
- To co-design strategies for increasing CYP's awareness and understanding of HSC research
- To explore the barriers and challenges CYP encounter when invited to participate in HSC research design and delivery, informing both local and national communications strategies for improved involvement
- To advocate for the meaningful involvement of CYP at a strategic level within HSC organisations.

1.b. Organisation

The event was planned by a group of 7 young people (4 boys, 3 girls aged 14-18 years old) from 4 national GenerationR Alliance affiliated Young People Advisory Groups (YPAGs) and facilitated by the coordinators of GenerationR Alliance.

The planning group met online 5 times over a 4 month period in the lead up to the event. They contributed to the full planning of the event including;

- Refining the objectives of the day to make sure they were relevant to CYP
- Developing the activities and agenda and agreeing the location, logistics and layout of the venue
- Designing the promotional materials
- Choosing the menu and advising on how to ensure the event was accessible and enjoyable for CYP.

Positive feedback was received from the CYP planning group about their experience of participating in the event planning process:

> **I loved being part of the young person's planning team! Planning such a large project, collaboration with other young people, and encouraging discussions on youth led research showed that young people can lead and create a more inclusive and equitable society.**

> **Being involved in the planning process made me feel like my opinion matters. I think the meeting made young people like me feel valued for who they are.**

1.c Delivery

Delegates

The event was publicised through existing Young People's Advisory Groups (YPAGs), the National Health Service England (NHSE) Youth Forum and Regional Research Delivery Networks.

Patient and Public Involvement and Engagement (PPIE) facilitators invited CYP through their networks, with a maximum of 5 places per group to ensure a broad regional representation of CYP. Consent to attend and photographic consent were managed directly by PPIE facilitators.

The groups who attended were:

- Bristol YPAG (NIHR Applied Research Collaboration West)
- Moorfields eye YPAG (Moorfield NHS Trust)
- Leeds Young Research Owls (Leeds Teaching Hospital NHS Trust)
- Kent, Surrey and Sussex YPAG
- Young Research Champions Group (NIHR Research Delivery Network (RDN) West Midlands)
- Herts YPAG (University of Hertfordshire)
- Young Dynamos (Bradford District Care NHS Trust)
- Liverpool YPAG (NIHR Alder Hey Clinical Research Facility)
- Kent Youth Research Network (Kent County Council)
- NHSE Youth Forum (National)
- GOSH YPAG (Great Ormond Street Hospital, Biomedical Research Centre)

In total 51 CYP and 37 adults attended the event.

1.d. Topics

The agenda for the day included a mix of presentations and workshops covering the following topics:

- The importance of involving CYP
- How involving CYP works in practice
- Trauma-informed approaches to CYP's mental health involvement in research
- The ideal researcher through the eyes of CYP
- CYP involvement at every stage of the research journey

The planning group, composed of young people and support staff, collaborated through several sessions to determine the most relevant topics and suitable formats for the event. They prioritised discussions around issues important to Children and Young People (CYP) and selected engaging topics with varied activities to ensure inclusivity, active participation, and enjoyment for all attendees.

2. KEYNOTE SPEAKERS

During the event a number of keynote speakers were invited to present their work with CYP.

Below is a summary of what we heard:

Cath Larkins: Trauma-informed approaches to CYP's mental health research.

Cath Larkins shared her experience of peer research and covered important considerations for CYP involved in HSC research. These included;

- planning for safeguarding when taking part in HSC research
- conversations which can be triggering for CYP
- involvement roles that are suitable for different types of people depending on their personal experiences.

Top tips for consideration (knowing ourselves):

SUPPORT - before and after activities

CAPACITY or **CRISIS** moment

RELATIONSHIPS - people in the room

PROTECTION on-and off-line

TOPICS to be discussed and **TRIGGERS**

Sophie Ainsworth and **Dr Simon Stones**: Raising Awareness of invisible Illnesses in Schools and Education (RAiISE)

Sophie and Simon shared their personal journeys into health research and described how Sophie had founded the charity RAiISE, which seeks to increase awareness and understanding of CYP living with an invisible illness. RAiISE works to enhance recognition of these conditions within educational settings by developing tools and creating opportunities that support collaboration among CYP, families, educators, and health professionals.

Their presentation highlighted the diverse opportunities that involvement in health research has offered them, and they encouraged CYP to explore the potential pathways available within the research landscape.

Mary Busk and **Diana Boyd**: NHS England

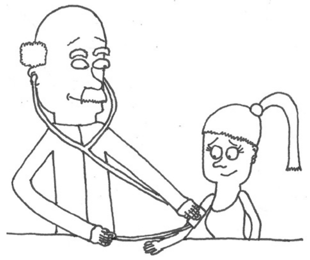
Mary and Diana explored the challenges of ensuring that every CYP's voice is meaningfully heard in research. Their presentation underscored the importance of inclusive practices, particularly in amplifying the voices of CYP with learning disabilities and special educational needs. They emphasised the need for HSC research to be accessible and beneficial to all, highlighting the responsibility of researchers to create spaces where diverse experiences and perspectives are recognised and valued. Mary and Diana emphasised three key areas:

1. **Ensuring research benefits** all CYP: Research should take place in accessible locations and focus on issues that matter to a wide range of CYP. Funding should be directed toward topics that reflect their diverse needs and priorities.
2. **Building inclusive research teams**: It's essential to create environments where every CYP feels welcomed and heard. This involves working with professionals who are skilled in involving CYP and are committed to incorporating their ideas and lived experiences into the research process.
3. **Identifying what truly supports CYP in health, and social care research**: This means looking at what works best for every CYP and making sure everyone's voice shapes research.

Louise Ting: Public Contributor

Equity and equality in setting and funding of research priorities

Building inclusive research communities with the right skills to include all voices



Evidencing what works in education, health and social care for everyone

Louise, introduced the research cycle, an accessible diagram co-developed by CYP, which illustrates how CYP, parents and carers can be actively involved at every stage of the research process. She shared her personal experiences of being involved in research and emphasised the importance of increasing representation and participation of under-served and neurodiverse voices within HSC research.

Read more about Louise's research cycle by visiting the NIHR Applied Research Collaboration West website.

Josh Harsant: Head of Influence & Voice at Barnados

Believe in
children
Barnardo's

Josh spoke about how Barnado's involves CYP in its work across the UK. He introduced the organisation's new three-year strategy for CYP involvement, which is grounded in a commitment to listening to and acting on the voices and experiences of CYP. Josh outlined Barnados' dedication to advocating alongside CYP and to creating meaningful opportunities for them to shape the future. He also presented the organisation's non-negotiable principles for engagement, which underpin this approach.

The non-negotiables

SAFE

Making sure children and young people feel and are kept safe and we work in a way which is trauma-informed and responsive.

ETHICAL

Making sure how we work is ethical, fair and respectful, and informed consent is obtained.

INCLUSIVE

Making sure we ensure equity of opportunity, actively removing barriers to working with us.

MEANINGFUL

Making sure opportunities we provide are genuine and at the right time, so children and young people can have a real impact.

BARNARDO'S

3. FINDINGS FROM CYP WORKSHOPS

During the event, CYP participated in a series of group discussions and feedback sessions focused on key themes, including:

- CYP involvement in practice: Exploring what meaningful involvement looks like for CYP involved in HSC research.
- The ideal researcher - heads, hearts and hands: Reflecting on the qualities CYP value in researchers, including knowledge, empathy, and practical skills.
- Why adults working in CYP HSC research should listen to CYP: Discussing the importance of valuing and acting on CYP perspectives.
- CYP feedback on the Patient Engagement in Clinical Development (PECD) service: Sharing insights and experiences to help shape future involvement practices, particularly in how CYP collaborate with life science industries.

Below is a summary of what CYP shared with us during the sessions:

3.1 How does involving CYP work in practice

This activity was part of a PhD project exploring what meaningful PPI means to CYP. All attendees were invited to share their experiences of involvement in practice.

Each CYP received a piece of bunting to write or draw their responses to two questions:

- How does being involved and having your say make you feel?
- If you could change one thing about your involvement, what would it be?

Adult delegates were asked two different questions:

- What has been your most rewarding experience working with young people?
- If you could make one wish for the future of CYP's involvement, what would it be?

Once finished, they shared their answers with others at their table and to the wider audience. The summary below captures the core messages:

Feedback from CYP

How does being involved make you feel?

CYP described feeling empowered, heard, and valued through their involvement in HSC research and engagement activities. Many expressed pride in knowing their voices contribute to meaningful change and appreciated being recognised as equal participants. Involvement made them feel connected, respected, and part of a wider community. They felt they had opportunities to learn, share experiences, and influence decisions. They highlighted the importance of inclusive spaces where their ideas are welcomed, and where they can see the impact of their contributions. Overall, CYP reflected on their involvement as inspiring, rewarding, and a source of personal growth and confidence.

If you could change one thing, what would it be?

CYP reflections on how their involvement in research and engagement activities could be strengthened CYP expressed a desire for broader inclusion, both nationally and internationally, emphasising the importance of diverse voices and perspectives. Many called for more consistent and meaningful involvement throughout all stages of research, with regular updates and feedback to understand the impact of their contributions.

A recurring theme was the need for genuine respect and recognition, with CYP wanting to be truly listened to and appreciated for their time and insights.

Clearer, more accessible communication was also highlighted, alongside easier ways to connect with decision-makers, particularly within the NHS and life sciences sectors.

CYP advocated for more creative and varied opportunities to share their experiences, and for greater visibility of their contributions.

Finally, they expressed enthusiasm for increased opportunities to collaborate, attend events, and contribute to a wider range of projects, valuing fun, structure, and the chance to learn and lead.

Feedback from adults working with CYP

Most Rewarding Experiences

- **Empowerment and Growth:** Adults described the joy of supporting CYP to build confidence, recognise their value, and thrive in education and healthcare settings.
- **Creative Collaboration:** Co-developing tools such as a health passport was highlighted as both enjoyable and impactful in improving care.
- **Resilience and Transformation:** Witnessing CYP overcome personal and systemic challenges, including recovery journeys and transitions into adulthood, was deeply meaningful.
- **Public Engagement:** Seeing CYP present at national conferences and engage in peer support demonstrated their capability and maturity.
- **Safe and Inclusive Spaces:** Creating environments where CYP feel confident to 'take up space' and share their experiences was seen as essential to meaningful involvement.
- **Long-Term Relationships:** Being recognised as a trusted adult years later reinforced the value of sustained, supportive engagement.

What adults would like to see change

Inclusion of more diverse voices

- A strong desire to ensure younger children, those with different communication needs, and CYP with severe learning disabilities or who are nonverbal are actively seen, heard, and valued.
- Calls for broader representation, including disabled CYP and those from diverse socioeconomic and ethnic backgrounds.

Accessibility and equity

- Wishes for more accessible spaces, inclusive leadership, and tailored approaches that meet CYP where they are.
- Emphasis on reaching isolated or less-engaged CYP through peer-led approaches and varied communication methods.

Structural support and recognition

- A need for secure funding and formal recognition of CYP involvement, including support for running young person's advisory groups (YPAGs).
- Advocacy for legal and structural accountability to CYP in all involvement activities.

Integration across sectors

- Aspirations to embed CYP involvement beyond health, into schools, local government, and primary care ensuring a holistic approach to involvement.
- Empowerment and skill-building
- Wishes for CYP to gain essential life and communication skills through involvement.
- Support for leadership development, empathy-driven advocacy, and the use of emerging tools like AI to amplify CYP voices.

Influence in research and policy

- Calls for CYP to be involved in designing clinical trials, sitting on ethics committees, and influencing funding decisions.
- Recognition of the value of qualitative data and lived experience alongside traditional research methods.

3.2 The Ideal Researcher; Heads, Hearts and Hands

In this activity, attendees were asked to consider their ideal researcher. Each group had an outline of a person on a large piece of paper, and was asked to write or draw how an ideal researcher might think, feel and behave, in the head, heart and hands of the body.

The aim of the activity was to explore the values, behaviours and knowledge young people would expect to see researchers demonstrate.

Below is a summary of what CYP told us:

Head - Think

Attendees wanted researchers to take an open approach to how they think about their research.

They should:

- Be open-minded and curious, ask open questions and be ready to actively listen.
- Retain a level of humility and compassion; they should remember that each individual will have their own unique experiences and perspectives.
- Think of the CYP as experts through lived experience, whilst CYP recognise they bring their own knowledge, it is important to recognise the value of CYP's knowledge.
- Think creatively about how they can engage and connect with CYP, how they can build trust, and create a safe and comfortable environment.
- Be mindful of the mental and emotional load that is associated with taking part in research and research engagement.

Heart - Feel

Attendees highlighted two key areas for feeling - how researchers should feel about the research, and how they should feel about those they are engaging with.

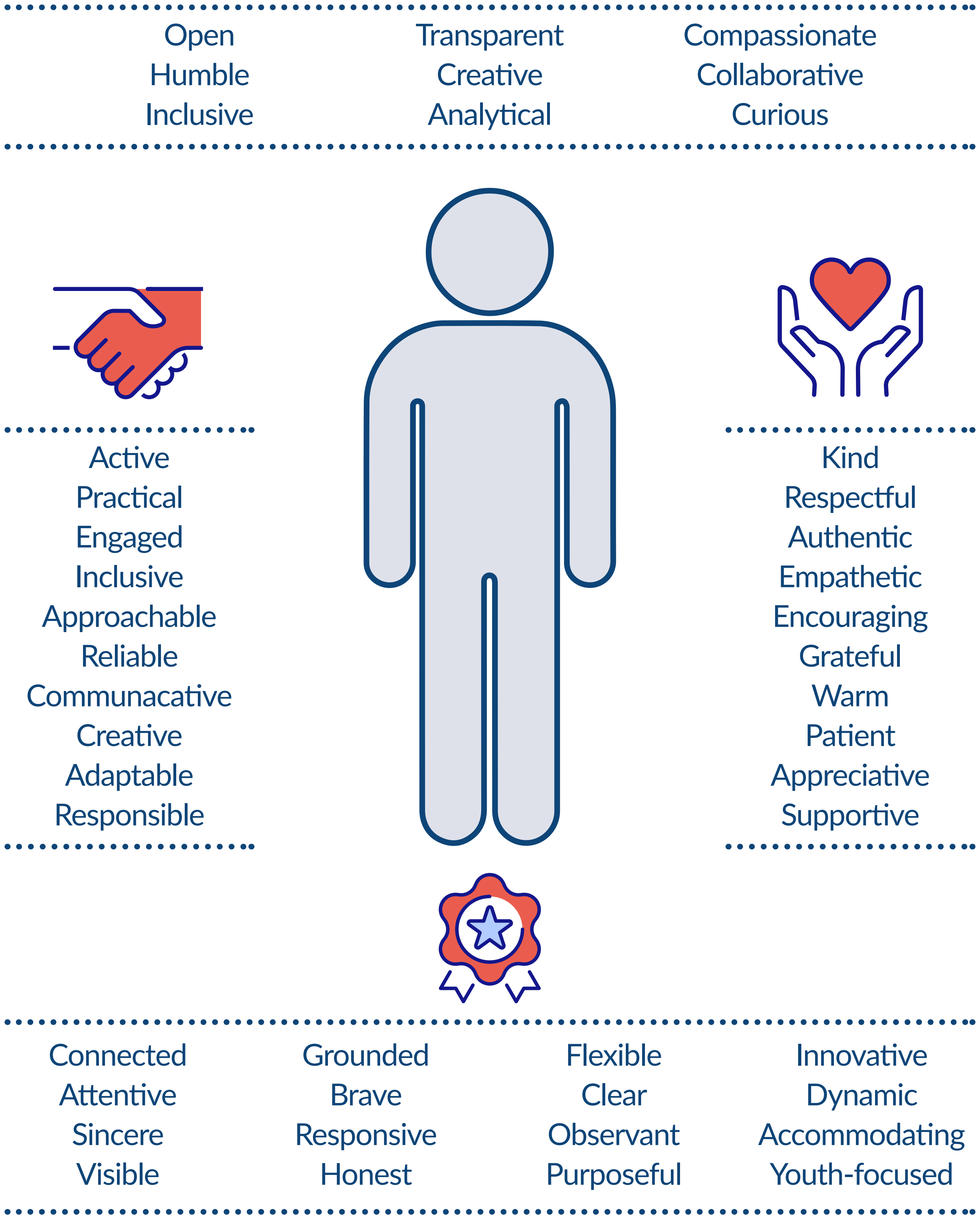
Researchers ideally should:

- Be openly motivated, passionate and excited about their research
- Be willing to change, based on the feedback they receive.
- Be empathetic, approachable, authentic and respectful.
- Be welcoming and enthusiastic about the engagement, showing genuine interest in the person's experiences and perspectives.
- Value the insights of CYP, and actively demonstrate that they appreciate their involvement.

Hands - Do

When engaging with CYP, the ideal researcher should:

- Avoid assumptions about who they are engaging with, but have the adaptability to meet young people at their level.
- Use clear, simple language and make the engagement fun and interesting for those involved.
- Be approachable and friendly, and aim to create a safe and comfortable environment for those involved.
- Allow plenty of time for each activity, to help build that relationship and space, and to ensure everyone feels they have had the opportunity to speak and be listened to.
- Following the engagement, they should give feedback to the CYP to demonstrate how their insights have been used and valued.
- Consider how they can build long-term engagement in the research and share the research outcomes.
- Researchers should ask for feedback to allow for continuous improvement of their engagement activities.



Open
Humble
Inclusive

Transparent
Creative
Analytical

Compassionate
Collaborative
Curious

Active
Practical
Engaged
Inclusive
Approachable
Reliable
Communacative
Creative
Adaptable
Responsible

Kind
Respectful
Authentic
Empathetic
Encouraging
Grateful
Warm
Patient
Appreciative
Supportive

Connected
Attentive
Sincere
Visible

Grounded
Brave
Responsive
Honest

Flexible
Clear
Observant
Purposeful

Innovative
Dynamic
Accommodating
Youth-focused

3.3 Why adults working in children's healthcare research should listen to the views of CYP?

Young people were asked at the end of the event to: "Share one reason why adults working in children's healthcare/research should listen to the views of CYP?" Here is what they told us:

Better Care and Support

The central theme was that including CYP's voices leads to better care and support. CYP have a unique understanding of their own needs, and by listening to them, adults can ensure that the care provided is more personalised, empathetic, and effective. Many responses emphasised how hearing CYP's views makes them feel valued, leading to higher self-esteem and confidence, which directly impacts their well-being.

> **Research and care directly impact children and young people. I think it is important that care is tailored to the needs of children and making them feel as comfortable and happy as possible to try and keep their experiences as pleasant as possible.**

Enhanced Research Quality and Relevance

Another prominent theme was the positive impact of involving CYP in research. Participants noted that research projects are more likely to be successful, relevant, and impactful when CYP's perspectives are included. CYP's lived experiences bring a fresh and essential viewpoint that ensures research is directly relevant to those it aims to benefit—CYP themselves.

> **Involving young people will provide better results than you could possibly get from adult led research. Young people are the experts on young people and a wider perspective is always better.**

Amplifying the Voices of the Future

The feedback also highlighted the broader societal and generational impact of listening to CYP. Many respondents emphasised that CYP represent the future, and their inclusion in healthcare and research processes is vital for creating sustainable, forward-thinking solutions. By involving CYP now, adults can help shape the more meaningful future research by ensuring that the needs and concerns of future generations are addressed today.

> **Let us show you, let us help you to make real change! We are the future, let us help in the present! Our experiences are invaluable to shaping and creating new realities for future generations! Just hear us!**

Meaningful and Impactful Change

Many participants pointed out that involving CYP in healthcare and research is essential for creating real, meaningful change. When CYP's experiences and opinions are taken into account, research becomes more grounded in the realities of those who are most affected. This leads to solutions that truly reflect the needs of CYP, promoting more effective interventions and support systems.

> **Research is not just about data it is about understanding people's lived experiences and realities and ensuring evidence translates to meaningful change.**

Respecting Rights and Ensuring Inclusivity

Participants also emphasised the fundamental right of young people to be heard. Many responses framed the involvement of CYP in research and healthcare as a matter of social justice, highlighting that it is essential to uphold their right to contribute to decisions that impact their lives. This perspective underscores the importance of inclusivity, ensuring that all voices—especially those of under-represented groups are amplified in research processes.

> **It's important because young people are the adults of tomorrow. They need their voices to be amplified in order for the rights and opportunities of the future children to thrive.**

Generating Innovative Ideas and Perspectives

The feedback also revealed that CYP bring fresh, innovative ideas that can drive meaningful change. Their unique outlook on the world provides new solutions and their creativity and insights can lead to breakthroughs in research and healthcare practices that adults may not have considered.

> **Children's voices give a new perspective and help them feel heard and understand what's happening. It also helps raise awareness and keeps kids involved.**

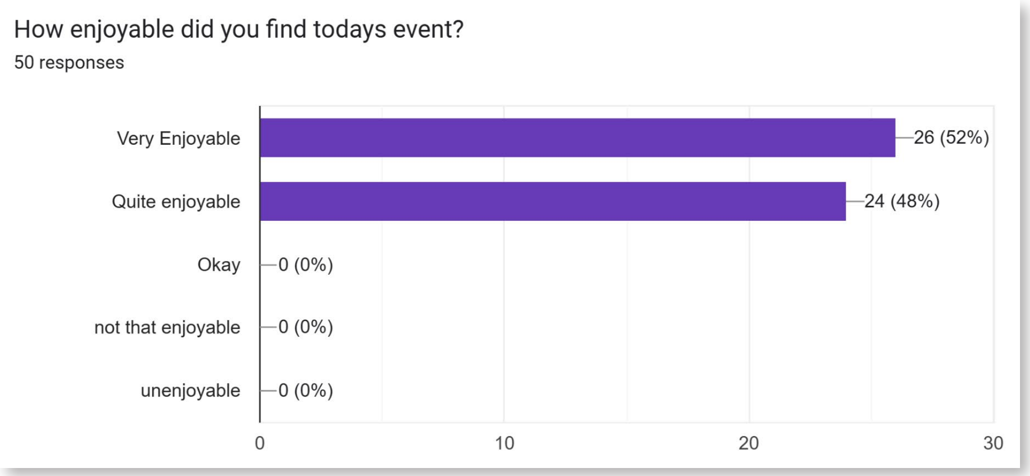
3.4 Patient Engagement in Clinical Development (PECD) service - CYP Feedback

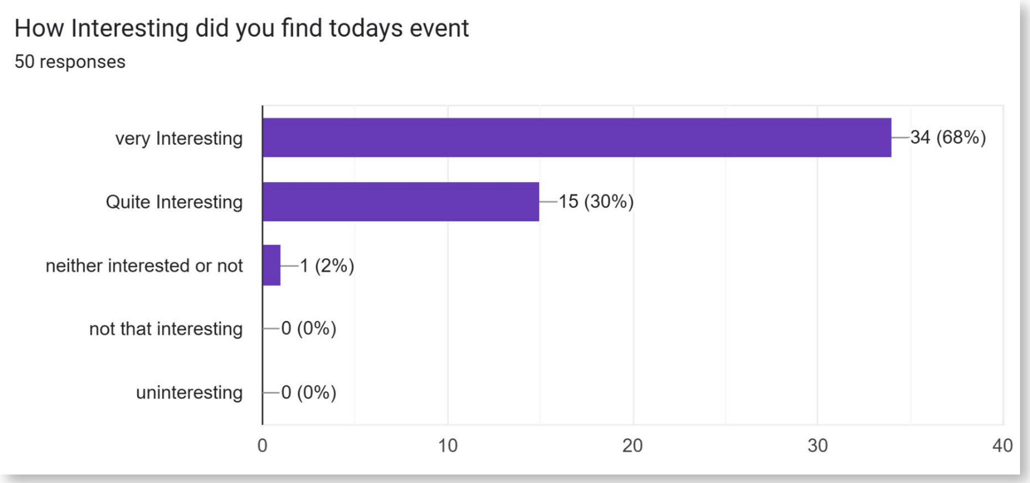
A representative from the PECD service engaged with CYP during the event to gather feedback on how the service could be improved to better support CYP involvement in the future. The team also explored how CYP prefer to share feedback about their research experiences. Most CYP indicated a preference for written surveys (53%) or in-person discussions at workshops (37%). Additionally, a significant majority (82%) felt it was important to know who was funding the research.

CYP identified schools and GenerationR as their preferred channels for hearing about new opportunities to get involved. They also emphasised the importance of fair compensation, expressing that CYP should be paid for their time just as adults are. CYP wanted a clearer understanding of the purpose of the PECD service and suggested more engaging ways to provide feedback, such as using coloured cards. Additionally, they recommended that the PECD team make their communications more accessible and visually appealing to better capture CYP's interests.

4. Making Connections event evaluation

A total of 50 feedback forms were received from delegates, including the young people attending and staff. A summary of responses can be found below:





All attendees found the event enjoyable and engaging. The CYP, in particular, appreciated the chance to connect with one another, share their perspectives, and explore research alongside their peers. They were especially inspired by learning about the wide range of initiatives aimed at involving CYP in research, and the value placed on their contributions across the healthcare and research system. The opportunity to deepen their understanding of how research works, discover ways to get involved, and see the impact of their involvement was something they truly valued.

The overarching theme in suggestions for improving the event was simply: more.

Attendees expressed a desire for more time together, more opportunities to connect and share, more chances for CYP to lead discussions and present their ideas, and more pathways for continued involvement moving forward. Their enthusiasm to contribute to HSC research was unmistakable. Yet, as one attendee insightfully noted, the event felt like “preaching to the converted”. The next challenge lies in finding ways to “invite others to listen and learn”.

5. Sharing the findings - Reconnecting Webinar

On 1st May 2025, the planning team hosted a follow-up webinar titled ‘Reconnecting’. The purpose of the session was to emphasise the significance of CYP’s voices to stakeholders across the broader health and care system, and to share key insights from the in-person event, as detailed in this report.

Attendees were invited to make a pledge, outlining how they intend to engage with CYP in the future.

The webinar featured a series of insightful talks, including:

- Why are CYP voices fundamental to the success of the NIHR? **Prof Monica Lakhanpaul** - NIHR National Specialty Lead for Children, Professor of Integrated Community Child Health
- Co-designing the event with children and young people. **Jennifer Preston**, Patient and Public Policy Manager, University of Liverpool, Generation R Alliance Coordinator
- Outcomes from the Making Connections Event. **Heather Slade**, Strategic Partnerships Lead, NIHR Research Delivery Network
- Making Connections - Involving Children and Young People in Research. **Dr Steven Parks**, Research Manager, Diabetes UK
- CYP Voice and the Department of Health and Social Care. **Mickey Conn** - Research Programme Lead (Children and Families), Department of Health and Social Care.

146 people registered for the webinar, and 73 attended on the day. Attendees covered a wide range of stakeholder groups, with representatives from:

- Charity organisations
- Lifescience companies
- CYP community groups
- NHS research and PPIE teams
- Academic and clinical researchers
- Teams across the NIHR infrastructure
- Department of Health and Social Care

The virtual pledge board captured a wide range of commitments to amplifying CYP voices in HSC research. Attendees pledged to continue championing the involvement of CYP, advocating for their inclusion earlier in the research lifecycle. Many committed to expanding opportunities for CYP, exploring and addressing the barriers to involvement, and improving accessibility. A strong theme also emerged around fostering collaboration across the system and sharing best practices, working collectively, to ensure CYP voices are heard and valued.

The webinar was recorded and shared with all registrants via Eventbrite, with encouragement to circulate it further within their networks. It was also distributed more broadly across the NIHR RDN network, and shared with charity partners through the Association of Medical Research Charities (AMRC).

The recording can be viewed here:
https://shorturl.at/HTxGs

A summary of the pledges from the webinar is provided below.

6. Next steps

1. Sharing the outcomes

We will disseminate the event report and key findings to influential stakeholders and decision-makers across the HSC research landscape. To support deeper involvement and engagement, we plan to organise targeted meetings that will explore the findings in greater detail, including:

NIHR Public Partnership Board
The findings from the event were presented to the NIHR Public Partnership Board on 10 March 2025. During the meeting, Sammy Ainsworth (GenerationR) and Gwyn Cracknell (RDNCC) shared a summary of feedback from CYP. They highlighted key barriers to involvement and engagement alongside the challenges when funding CYP involvement activities. The presenters called upon board members to reflect on how CYP involvement is embedded and resourced within their respective areas of the NIHR.

CYPPPIE National collaborative meeting
The #CYPPPIENatCol brought together a vibrant mix of researchers, nurses, network staff,academics, and colleagues from Trusts and the RRDN all united by a shared commitment to involving CYP in HSC research. The event showcased a range of inspiring initiatives, including innovative podcasts co-produced by CYP between the ages of 6-10 years old, living labs, and insightful projects,all focused on amplifying CYP voices across the research landscape.

The meeting was both energising and thought-provoking, helping us identify the key partners and stakeholders needed to build lasting frameworks for meaningful CYP involvement. This work is essential to ensuring that CYP not only have access to research but also experience the benefits of active involvement and engagement.

We left the event with a wealth of ideas on how to broaden inclusion, strengthen involvement, and collaborate more effectively. Our next step is to explore how we can work together across the NIHR to create sustained, meaningful opportunities for children and young people to shape HSC research..

2. Creating the ideal researcher Resource

Building on the 'ideal researcher' activity, a dedicated resource will be developed and shared with researchers via the RDN. This resource aims to raise awareness of the values, behaviours and knowledge that CYP believe researchers should embody when conducting research involving CYP It will serve as a practical guide to support more respectful, inclusive, and effective involvement and engagement.

3. Patient Engagement in Clinical Development Service (PECD)

Insights from the event are being used to inform the development of a new offer within the PECD Service. This will enable researchers to gather input directly from CYP, moving beyond the current model, which primarily captures perspectives from parents and carers.   A report capturing insight from this insight session is available here

4. Children and Young People's Patient Research Experience Survey (PRES)

During the event, CYP expressed a strong interest in sharing feedback about their experiences of participating in research and offered a range of creative ideas on how this could be done. The NIHR RDN currently runs a national Participant in Research Experience Survey (PRES). Building on the insights from the event we will work with CYP from across the country in co-design a future-facing PRES, one that is engaging, inclusive, and tailored to the needs of CYP, by March 2026.

5. The NIHR Research Delivery Network

The NIHR RDN is currently undergoing a period of transformation and reorganisation. As part of this process, we are committed to embedding the voices of CYP wherever possible into future design of public involvement and research inclusion activities.

6. How does involving CYP work in practice?

Insights from the 'How does involving CYP work in practice?' workshop will contribute to a PhD project focused on understanding what meaningful patient and public involvement means to CYP, and how it can be effectively embedded within HSC research organisations. These insights will contribute to the research outputs, which are intended for publication. Once available, the results will be shared with all participants involved.

Acknowledgements

We would like to thank the following people and organisations for their support and commitment to ensuring the Making Connections event and Reconnecting webinar were successful:

The CYP Planning Committee for the Making Connections Event

- **Lowenna Negus** - Bristol YPAG
- **Uduakabasi Asuquo** - VoiceUp, Manchester
- **Uwakmfonabasi Asuquo** - VoiceUp, Manchester
- **Rishi Muthu** - VoiceUp, Manchester
- **Toby Inwards** - GOSH, London
- **Lucy Inwards** - GOSH, London
- **Aleena Khan** - eyeYPAG, London

All children and young people and the PPI Facilitators and carers who attended the event
DHSC for funding the event.

Event speakers

Sophie Ainsworth and **Dr Simon Stones**; RAIISE
Professor Cath Larkins, **Josh Harsant**; Barnados, **Diana Boyd** and **Mary Busk**; NHSE,
Louise Ting; Public contributor

Webinar speakers

Steven Parks; Diabetes UK, **Jennifer Preston**; Generation R, **Monica Lakhanpaul**; RDN,
Heather Slade; RDN, **Mickey Conn**; Department of Health and Social Care (DHSC)

Other contributors to the day including

NHSE Youth Forum, Brighter, The Studio Birmingham, More than Minutes

Report written by

Jennifer Preston, Patient and Public Involvement Policy Manager at the University of Liverpool
Gwynneth Cracknell, Senior Manager for Public Engagement, NIHR Research Delivery Network
Isabella Darbyshire, Strategic Partnerships Delivery Coordinator, NIHR Research Delivery Network
Heather Slade, Strategic Partnerships Lead, NIHR Research Delivery Network
Samantha Kokovika, Strategic Partnerships Delivery Coordinator, NIHR Research Delivery Network

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