



Engaging young people in NHS service delivery and development

A scoping review of the evidence

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Executive summary

While there is widespread support for youth participation in the development and delivery of healthcare services, it is not very clear what is actually being undertaken in practice within the NHS, or what the evidence is for good practice.

We do have a fairly extensive literature on models of participation more generally that can be usefully applied to this context, and a developing sense of the categories of engagement that are being employed in developing and monitoring health services for young people. However, this scoping review concluded that, in terms of good practice and what works, there is much less evidence available, and we know very little about how engagement ‘works’ for the young people involved.

Issues include confusion around terminology, a lack of clarity around conceptualization and theorization (why is participation being undertaken in certain ways?), and a sense that while lots may be happening on the ground, there is a lack of documentation or systematic delivery.

What does exist in the research literature suggests that much of what is going on is piecemeal, short lived, or lacking clear aims and outcomes. While there may be a fair amount of consulting and informing taking place, truly empowering models of participation are rarely documented. There is clearly a need for more evidencing, both in terms of a description of what is undertaken, but also analysis of impact.

Where we do have reports, articles, book chapters, websites, blogs and other accounts, they have long suggested a consistent set of features that are important for effective youth participation. These include appropriate institutional and policy supports, clear understanding of how to work with young people, the importance of professional skills, and investment in communication, documentation and evaluation as well as staff time.

The conclusions we draw are no different to those of similar reviews undertaken up to a decade ago, or of parallel reviews undertaken in relation to youth participation in health research studies. Finding ways to improve the evidence base is now critical if participation is going to have the transformative impact on the system that it has the potential to achieve.

Introduction

Young people need to be involved at all levels of our healthcare system, from shaping the care they are receiving at the front line right up to co-designing and inputting to strategic change. Apart from anything else, their right to input in issues affecting them is enshrined in the 1989 UN Convention on the Rights of the Child, particularly in Article 12. The application of these rights to children's healthcare are widely reflected in policy documents (eg, Davies, 2013; NICE, 2021; NHSE, 2022).

What we mean by health services in this context is any NHS funded or branded service that manages the health and wellbeing of young people (10-25 year olds), ranging from primary care, through secondary and tertiary services, and including community services, mental health services, and allied health professional services such as physiotherapy and occupational health.

NHS England is committed to working in partnership with young people but this requires planning, resources and guidance. It can also mean different things in different parts of the systems or at different levels of service planning and delivery. Despite high levels of commitment to working together with young people and representing their voice in policy and planning, in practice our understanding of what is actually happening on the ground within the system is somewhat lacking. NHSE's Children and Young People's Transformation Programme commissioned this project to map the territory and provide an understanding of what we do and do not know about best practice in this area.

We have focused on participation and engagement in service design and development only, excluding projects on young people's engagement and participation in research projects unless they specifically shed light on participation in the practice context. The evidence base on involving young people in research is related, but different, to that on participation in service design and delivery. Many research projects will now include young people as advisors or consultants at some point during the research cycle (see NIHR, 2021, for more information), but the issues can be distinct from those implicated in young people's involvement in service design and delivery. One of the main differences for example is that service engagement often relies on young people with quite substantial lived experience and this brings different safeguarding and support needs.

This scoping review is one of two reports by AYPH published simultaneously, together with a separate [set of recommendations](#). The second report is an [account of our own research](#) to assess the range and type of participation activity that is ongoing within the system at the moment, drawing on a survey and series of interviews with people working in the NHS. Both reports come to very similar conclusions, and complement each other. The recommendations pull together suggested ways for improving the evidence base.

Key questions

- What do we mean by youth participation in healthcare and what models of youth participation in healthcare exist?
- How are young people currently being directly involved in design, delivery and evaluation of services in healthcare?
- What do we know about the evidence on the enablers and challengers to doing youth engagement work in healthcare?
- Where are the research gaps?

Methods

This is a preliminary scoping review, setting out the general territory and starting to assess what we do and do not know. It is not a systematic review, but rather highlights some of the key themes arising from the research and evidence we have to date.

Methods included a mix of database searches, snowballing of references from existing papers, professional knowledge and grey literature/web searching, including searches of websites and online resources such as Healthwatch, the Anna Freud Centre website, the National Association of Patient Participation website, previous AYPH work, the websites of the royal colleges including the Royal College of Paediatrics and Child Health, charities such as the NSPCC, the James Lind Alliance, and the Patient Experience Network.

Social policy and practice databases and Pubmed searches were undertaken using search terms such as “young people OR “adolescenc* or youth”, “engage* OR collabora* OR co-produc*”, “service development OR health service OR quality improvement, and “Participation OR co-produc* OR engage*”.

The searches resulted in approximately 600 potentially relevant titles on all platforms, of which less than 20 were assessed as relevant after a title and abstract review, and some of which overlapped or related to the same project. We then expanded this through snowballing techniques to a total of 34 papers, reports and resources that were included in this final paper.

Results

A primary result from our scoping exercise was there is a lot of ‘noise’ around youth engagement but much less available in terms of what we might classify as traditional research activity on how to actively involve young people in health service design and development. We do have a fairly extensive literature on models of participation more generally that can be usefully applied to this context, and a developing sense of the categories of engagement that are being employed in developing and monitoring health services for young people. However, in terms of good practice and what works, there is much less evidence available, and we know very little about how engagement ‘works’ for the young people involved.

There is also a muddle over terminology, which becomes apparent very quickly in a scan of the evidence. Indeed, many of the examples that were thrown up by the searches related to increasing engagement or participation in personal care pathways or young peoples’ own individual treatment, which is different from participation in service development. There was much less on the description, analysis and evaluation of programmes to include the voices of young people in health service development work, or – even more empoweringly – in the process of co-producing change and improvement with young people. The situation is very similar to that reported in studies of children and young people’s patient and public involvement in health research (Rouncefield-Swales et al, 2021).

We present the main themes arising under each of our original research questions.

What do we mean by youth participation in healthcare and what models of youth participation in healthcare exist?

As Brady (2020) stated, there is no shared understanding of the meaning of participation in the health service context. Depending on how participation is understood, different conceptual and theoretical approaches may result. As a result, sometimes we are comparing apples with pears. The terms ‘participation’ and ‘engagement’ are used for a range of different kinds of activities, as is patient and public involvement and engagement (PPIE) and patient and public voice (PPV), and these are accompanied by (or interchangeable with) a range of others including – as spelled out by Rouncefield-Swales et al (2021) – participatory design, community-based participatory research, co-design, co-production, co-operative inquiry, and experience-based co-design.

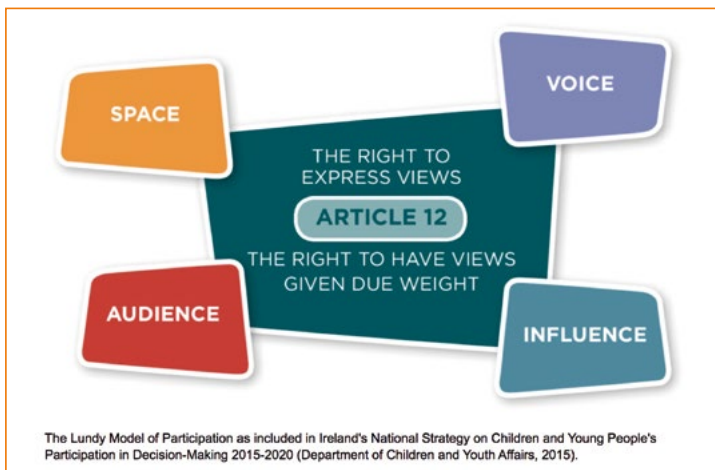
Brady (2020) and others argue that the culture of participation in any individual part of the NHS is just as important as the ‘level’ or type of participation being attempted. The culture needs to reflect a shared ethos where participation is not just a single event, but part of a belief in how to improve services, and a commitment to shared decision making. As Picton-Howell (2020) describes so powerfully in relation to the advocacy undertaken by her son during his short life, shortfalls in professional education and guidance can lead to unwillingness by professionals to encourage participation. Academics have also noted variations in the value given to patient information and power-sharing among different professional groups or organisations (O’Shea et al, 2019; Ocloo and Matthews, 2016). Indeed, the issue of culture in

holding back participation by children and young people was one of the major issues raised by Weil et al (2015) in their assessment of where we were at that time (nine years ago) in hearing the voices of children and young people in health.

Beyond the issue of underlying ethos or culture, there are a number of frameworks for classifying the kind of activities that are undertaken under the youth participation banner, that can help us to assess what is going on. Accounts of these often start with an early and widely used framework called the 'ladder of engagement' (Arnstein, 1969). Also popular is Roger Hart's Ladder of Children's Participation (1992) which describes eight ascending levels of decision-making agency, control, and power that can be given to children and youth by adults. Most

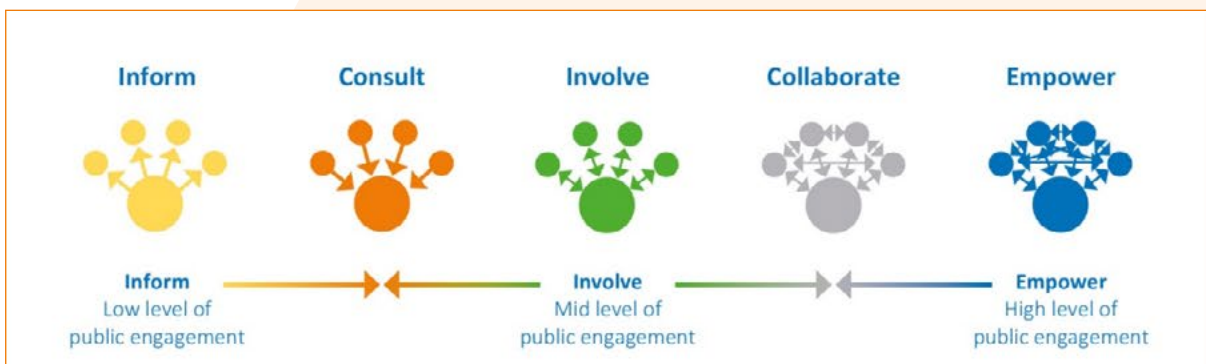
other models and guidance notes build on these levels, such as the NIHR (2021) briefing notes for researchers – public involvement in NHS, health and social care research (noting again however that these relate to research, not to service development). Similar models are deployed in other fields such as youth participation in policy making (Macauley et al 2022).

Key models with widespread recognition in the youth health field currently include those of the International Association for Public Participation (2018) (another more traditional 'ladder' model), and Lundy (2007) (a way of conceptualising a child's right to participation). The main elements of these are presented in **Figure 1**. In both cases the intention is that different kinds of participation activity can be classified by



Lundy model (2007)

FIGURE 1: Illustration of two models of youth participation in the health service sector.



A spectrum of public engagement (adapted from International Association for Public Participation, 2014)

the extent to which they include the various elements (consultation, collaboration, ability to influence, etc). While there is an important place in both models for being informed and consulted, the ultimate aim is empowerment or influence.

While both these two frameworks are useful and widely used, what neither does is differentiate between the structures put in place for participation (for example, one off groups versus youth forums), and the content of the activities that take place within those structures (for example, the extent of power sharing). As we will see, this becomes an issue when trying to classify and compare activities. Overall, it seems likely that taking a number of different perspectives on what is going on is important to get a rounded view.

How are young people currently being directly involved in design, delivery and evaluation of services in healthcare?

There are a number of individual accounts of episodes of youth engagement in health services, but nothing in the UK to date that provides a comprehensive, current overview of what is going on in practice. The individual accounts provide a sense of the range of activity and the challenges that people experience, although they vary hugely in terms of the comprehensiveness and quality of reporting. However, a previous scoping review does exist on the kinds of children and young people's PPIE in health related research (Rouncefield-Swales et al, 2021), where a similar exercise was undertaken in relation to research projects on health. As it transpires, and not surprisingly, there is a lot of overlap, but the academic research world provides a rather different kind of environment and professional context to that available in most busy hospitals or local GP surgeries.

The responses to our searches produced examples that can be set into the different levels of the participation spectrum of engagement described above (International Association for Public Participation, 2018).

As noted, this is just one way of looking at what is going on:

- **Informing:** At the most basic level of participation, young people can be informed about what is available. Examples that fall into this category include letting schools or other institutions know about the availability of new services for young people, writing leaflets about services specifically for youth audiences, or providing adult free days at a GP surgery in order to allow young people to understand what happens (as documented in PEN, 2015). However, such activities would probably not qualify as some kind of participation unless young people have somehow been involved in the process (perhaps they were consulted on who needed to be informed?), and drawing a line here between what is and is not participation is difficult. Unlike other categories in this list, informing is perhaps less of a useful engagement technique where the aim is to make progress and deliver change. However, it is an important process, and unfortunately in some ways the 'informing' category is one of the under-populated ones in this list in terms of publications. This may be because there is no obvious audience for explaining how you are communicating with young people; these kinds of exercises do not often add up to enough material for an academic article or a report, and are often simply considered to be a routine part of good practice.

- **Consulting:** Again, the distinctions between consulting, involving and empowering can be difficult to establish in practice. We have erred on the side of caution, but some examples included here could equally be pushed higher up the ladder. Published descriptions of consulting with young people in service design and delivery include the following:
 - Use of questionnaires or interviews to assess views. For example, Hackett, Mulvale & Miatello (2018) used this method to work out what was best for young people’s mental health services. Similarly, see Collins et al (2017) in relation to CAMHS, and much older examples in Lightfoot and Sloper (2002). These kinds of consultations are often used for a specific purpose in a specific service – consultation around a particular moment of change, for example. The materials used are usually ad hoc and designed by staff for the current purpose, not standardised instruments. It might be useful if more was known about available methods for this kind of consulting. At the simplest level, for example, this could include the Picker Institute’s children’s version of the Friends and Family Test (Picker Institute Europe, 2015).
 - The purely consultative elements of Young People’s Advisory Groups, Forums or Councils. More empowering elements of these structures fall into the next category (“involving”, “collaborating” and “empowering”). There are many examples of these kinds of structures from across the UK (eg, Street et al 2015, Birmingham model; Alder Hey CYPH Young People’s Forum; Great Ormond Street Hospital’s Young People’s Forum; Coad et al, 2008; Wittmeier et al 2023). They tend to be standing arrangements, looking at a range of issues over time.
- Other kinds of youth advisory groups, such as Youth Involvement Groups – an example of which has been reported at Bristol & Weston hospitals, where young people help to identify priorities, get involved in recruitment, and engage with other stakeholders such as the Clinical Commissioning Group (in the days when these existed). This was the winner of a PEN award in 2021 (Reynolds et al, 2021). There are quite a number of examples of young people presenting to various NHS executive boards of one kind or another on these kinds of topics (see Street et al, 2015).
- **Involving:** In an article on the meaningful involvement of children and young people in health technology development, Wheeler et al (2022) explain the benefits as children and their families providing “context, insight, personal experience and tacit knowledge to ensure that the end-product is usable, acceptable and can be integrated into its intended environment”. This seems a good definition of involvement. Some other examples in the literature include:
 - Engagement of young people as ‘secret agents’ or ‘secret shoppers’ (Street et al 2015, Southampton example; Young Healthwatch Hillingdon, 2019)
 - Liaison between schools (or other agencies) and health services. For example, the literature includes an example of young people from local schools invited to become ‘ward inspectors’ at a hospital. Sixth formers volunteered in children’s services, which may help prepare children who may need to come to hospital in the future (Milton Keynes, documented in PEN, 2015).

- Longer term elements of the more formal consultative structures listed above. Often young people can have a long term relationship with a forum, lasting for years. Whiting et al (2018) published a descriptive article about the work of the NHS Youth Forum, concluding that the members were committed to their role and their work was having a positive effect on health service provision.
- Involvement of children and young people in formal Quality Improvement (QI) projects within the NHS. For example, NELFT NHS Foundation Trust has documented the start of a QI project involving children and young people, intending to achieve a 25% increase in discharges from Havering Child and Adolescent Mental Health Services (CAMHS) by June 2024 (NELFT, 2023).
- **Collaborating:** At this point in the ladder of participation the expectations around power sharing between young people and professionals become more explicit, and the challenges perhaps more salient. These kinds of participation are rarer; they require considerable time, investment and skill on the part of both staff and young people. On the other hand, perhaps because this is a more challenging kind of work these projects are better documented in the literature – there is more of a story to tell, and more impact to share. Some examples include:
 - Co-design events and use of a framework (Hackett et al 2018).
 - Young people being developed to work as volunteers on programmes (Street et al, 2015, Nottingham example)
 - Co-design of an innovative group clinic model (TOGETHER project) for young people with diabetes (Papoutsis et al 2022)
- Again, there are occasional descriptions of collaboration relating to a number of formal structures such as the NHS Youth Forum, but these are rarely formally described. Occasionally they emerge from young people’s own accounts of their engagement in these activities (BYC, 2022).
- Enabling young people to write up their experiences and views in order to take part in advocacy and policy work, such as the young people’s chapter in RCPCH’s (2021) Paediatrics 2040 report.
- **Empowering:** This most demanding level of participation includes few examples, but again they are perhaps described in more detail than some of the simpler partnerships. Some of the examples already listed could arguably be included in this category – such as the work of the NHS Youth Forum for example, or the TOGETHER project’s co-design model, but it depends very much on the aim, content and consequence of meetings, and this is not always easy to determine. Involvement of young people in governance (as opposed to advisory groups) is important here, where they are engaged as equal partners in shared decision making groups. The distinction between consulting and asking for advice, and actively sharing power and decision making, is sometimes difficult to identify, or is not formally written up. In a review of shared decision making with young people, Watson et al (2023) concluded “methods of power-sharing do exist, but they have yet to be adopted by organisations”. Some published examples that we came across in the UK where it seemed there was active power sharing included:
 - The epilepsy youth advocates model developed by the RCPCH&Us team

(2022) could be construed as a full scale devolving of control to the young people involved, as they then went on to speak at national conferences and in NHS hospitals to improve epilepsy care for children and young people. The work developed into a tool for epilepsy clinics to review their own practice and improvement and has won multiple awards.

- The Manchester example presented in Street et al (2015) involved young people leading a ‘15 steps approach’ – a manager gives reports of the 15 steps and then feeds back to the group about what has been done (Thomas and Clarke, 2015).
- Establishment of a youth leadership team – see example in Street et al, Birmingham, which also include some young people undertaking social action leadership training with the hospital and a local university.
- The NIHR North Thames CLAHRC Young Commissioners model, co-designing community- based diabetic services responsive to the needs of children and young people (CLAHRC North Thames, 2018).
- Engagement of young people as non-executive directors In NHS Trusts (West Yorkshire Health and Care Partnership, 2022).

What does the evidence tell us about the enablers and challengers to doing youth engagement work in healthcare?

Drawing from the limited number evaluations of participatory practice with young people, and reviews of youth participation in the health setting, the following emerge as the critical enablers and challenges to date:

Enablers

● Policies and strategic leadership

- Allocation of responsibility at a senior level, to enable senior leadership and oversight (Weil et al, 2015; RCPCH 2012)
- Protection of staff time within the organisation, including investing time in building strong relationships (various, including review by Watson et al, 2023)
- Investment in building relationships between the youth advisory council (if that is what it is) and other parts of the system (Canas et al, 2021)
- Acknowledgement of the need for skilled staff. Some emerging evidence that involvement of trained youth workers can help with engagement and true participation (eg, Street et al 2015, Nottingham example)
- Creation of policies around remuneration & non-financial ways of compensating young people for their time and expertise (eg, Filipe, Renedo and Maarston, 2017; Van Schelven, 2020, NIHR Involve; Watson et al, 2023). Evidence suggests that compensation or paying young people for their involvement increases commitment and equalises collaboration (Van Schelven, 2020)
- Build in effective monitoring and accountability to ensure engagement is done safely, ethically and meaningfully (Hagell and Benniche, 2022).
- Make clear roles and responsibilities, including involving young people in what they want/can meaningfully contribute to (Van Schelven, 2020)
- Understanding clear boundaries – the line between participation and clinical work/intervention. Boundaries protect;

ethical guidance can advise, but it can still be hard to know how to put these into practice (Cody 2023).

- **Process**

- Involvement of young people early on in the process (various, including Kennedy, 2010, Van Schelven 2020)
- Designation of dedicated participation staff. Particularly important for building rapport and trust (eg, Cody, 2023)
- Clear articulation of the aim of the participation (Children in Scotland, 2019)
- Preparatory work with young people before meetings (eg, Canas et al, 2021; Westbrook et al 2021)
- Slowing down of meetings or rethinking structures to make them more youth friendly (Canas et al, 2021). All too often we expect young people to get involved on our terms, but traditional engagement approaches don't work for young people. Moving away from jargon-filled documents and meetings during school hours to more creative approaches can help us involve young people more effectively.
- Responding appropriately to context and changing participation methods to match (such as the pandemic; Brady et al, 2022; Westbrook et al, 2021)
- Building in variety and different ways to connect, including the use of creativity (Canas et al, 2021; Cody 2023; Watson et al, 2023). Allowing a range of different ways to engage may be productive – eg, Lister Young Voices group, where they use social media, web chats, and face-to-face meetings.

- **Communicating, documenting and evaluating**

- Feedback loops (various) – and the importance of being honest and transparent about what can and cannot be changed (eg, Canas et al, 2021)
- Evaluating the role of PPI in a project's outcomes (Van Schelven, 2020)

Much of this can be easier in dedicated children's hospitals, where there is a more resolute focus on the patient and family, as well as less competition for resource or focus (Patient Experience Network, 2015). Hospitals such as Alder Hey have demonstrated this with their widespread youth engagement, including a Youth Forum, a group on mental health called Transform, and a third consultation group called Camhelions.

As Van Schelven et al (2020) concluded, reflecting on the learning from PPIE with young people with long term conditions, *“Those lessons are divided into six themes, including practicalities to take into account at the start, involvement from the start, roles and responsibilities, support, flexibility and an open mind, and evaluation of process and outcomes...The lessons learned have taught us that meaningful PPI requires effort, time and resources from both young people and project teams, from the beginning to the end.”*

Challengers

These can be related to organisational and personnel issues, and challenges around the young people's own constraints.

In terms of organisational and personnel issues, this kind of participation work requires investment. The challenges are essentially the flip side of the enablers listed above, in that a lack of skilled staff, or adequate time, can make participation difficult to facilitate. It also requires clarity, and as Van Schelven (2020) concluded,

some project leads struggled to show the impact of PPI in projects and outcomes and a third of young people could not quantify the impact they had had on a project. This can result from the lack of clear, measurable aims.

Organisational challenges can also be posed by the high support needs of some young people with, for example, long-term or complex conditions – resulting in the need to recognise and support appropriately (eg, Richards et al, 2023). It is therefore vital that any participation work considers how to keep young people safe and managing the extent to which they share very personal and potentially distressing incidents with others.

On the other hand, wider representation of different groups of young people is essential if participation is to accurately reflect unmet need (Hagell and Benniche, 2022). In terms of the constraints that young people may face, many will find it difficult to participate for a range of reasons. Engagement with groups of young people from less heard groups requires high levels of staff time and contact to succeed. This is raised in many accounts across the board (Hagell and Benniche, 2022). The return on investment for staff can seem to be small in terms of the effort required, even to engage relatively small numbers of young people. On the other hand, putting in less effort can result in challenges around tokenism (eg, Richards et al, 2023; Ocloo and Matthews, 2015).

Particularly in terms of hospital engagement, young people can often be drawn from patients or students who want to be health care professionals. While they bring valuable enthusiasm and dedication, they may not socially represent all young people targeted by services. There are some examples of specific and targeted efforts to reach seldom heard

groups, such as one documented at Newham University Hospital, where the team worked with local schools and involved local specialist groups who could reach different local populations of young people. Reaching out into local community spaces seemed key here, but young people needed help to find a voice. The numbers who do finally engage can be very small (documented in PEN, 2015)

When participation depends on a young person's experiences, these may be deeply personal and emotive – such as participation in the development of mental health services for young people (Hackett, Mulvale & Miatello, 2018), raising the need for consideration of psychological impact or support. Many projects do not have any built-in feedback loop or evaluation of final outcome. However, one paper has discussed how, when participation is done well, co-production can contribute to an environment that is pro-recovery (Norton 2021).

What is not addressed in these kinds of lists is the challenge of matching the participation strategy to the aims of the project, service or exercise, or much on the direct and individual benefits to young people. This might include the extent to which there is a robust and honest discussion about the potential for real influence and change. We have not looked systematically at the evidence around impacts of participation on individual young people taking part, over and above good practice in relation to safeguarding, but there is a growing awareness that the impacts on the individuals taking part can be very positive (Weil et al, 2015; Hackett et al, 2018).

There also is less on the frustrations and negative impacts that presumably do exist where young people feel they were consulted but nothing changed – this was something raised with us by young people involved in our own work on the

ethics of youth participation (Hagell and Beniche, 2022; Common Room North and AYPH, 2021). There is also anecdotal concern and awareness of the potentially distressing or triggering impacts of having to discuss personal life events in public, but we have not found any concrete research evidence on this in relation to young people's participation in health service development. Ensuring the impacts on young people are considered and assessed will inevitably be part of good practice.

Finally, there are a number of guides on good practice when engaging young people more generally, but very much less that is specific to engagement in health service design and delivery. Some of the better known, general guides on youth participation in this context include:

- RCPCH (2010) [Not just a phase: A guide to the participation of children and young people in health services](#), and the college's more [general advice pages](#).
- AYPH's [general resources](#) site
- British Youth Council's guide on [Guide for involving young people in the NHS: Practical guide and checklist](#)

Where are the research gaps?

The research gaps relate to anything over and above descriptive reports on individual exercises in youth engagement, and even these are quite limited. As can be seen from the evidence review, there are very substantive research articles exploring the evidence for participation and these were mostly for one specific service. Therefore the biggest gap in research is that there is currently not even enough published literature to do a systematic review. Where evidence reviews have been attempted these are either mixed adult and young people participation papers (eg, Bombard et al, 2018, Ocloo and Matthews, 2016), focusing on research rather than practice (eg Rouncefield-Swales et al, 2021), looking at one type of participation only (eg, Watson et al, 2023) or again simply concluding that there is a lack of evidence (eg, Weil et al, 2015).

As Rouncefield-Swales et al (2021) comment in their review of children and young people PPIE in research, *"Of the studies which presented evaluation methods most reported relatively simple descriptions of the impact of PPIE based on informal evaluations and often insufficient detail was presented."* As a result, *"the evidence base on the impacts of PPIE remains patchy and largely observational"*; and *"the majority of this evidence on impacts was anecdotal."*

Conclusions

There is a lot of interest in, and experimentation around, youth participation in the development of health services. We know quite a lot about the possible range of ways in which young people could be engaged in health service design and delivery.

However, much less is known about what is actually going on at any given time across the whole health system. We have a sense of the models being employed, and pointers to good practice, but we do not know much about the details of what is being delivered, or the impact or effectiveness of different models.

As Rouncefield-Swales et al (2021) note in relation to the involvement of children and young people in health research, it is clear that youth participation is feasible. The issues are around appropriate implementation, systematic documentation and measurement of impact. They comment on “poor quality reporting of definitions, underpinning theory, and the evaluation of PPIE impact”. In this respect, participation by children and young people is no different to that of other patient groups (Ocloo and Matthews, 2016). These issues are also, unfortunately, almost exactly those summarised by Weil et al (2015) nine years ago, (or indeed Cavet and Sloper 20 years ago) in their assessment of how children and young people’s participation in healthcare was progressing at that time. The steps that are needed to improve the situation are still the same as they identified then – better dissemination of good practice, better evaluation, improved training and staff support.

Guidance needs to be pragmatic and flexible. Our conclusion is that aiming for full participation is not necessary, and may indeed be intimidating if people are starting from scratch, but improving how we do any at all is critical, as is documenting these approaches.

The lack of evidence itself may be contributing to the difficulties of placing young people’s participation higher on the agenda for individual NHS institutions. Helping to promote more accounts of what is going on is critical.

References

- Arnstein S (1969) A ladder of citizen participation, *Journal of American Planning Association*, Vol. 35, No 4, July, pp. 216 – 224.
- Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., ... Pomey, M. P. (2018). Engaging patients to improve quality of care: *A systematic review*. *Implementation Science*, 13(1). <https://doi.org/10.1186/s13012-018-0784-z>
- Brady, L-M. (2020). *Embedding young people's participation in health services: new approaches*. Policy Press.
- Brady, L.-M., Bray, L., Beeden, E., Davies, S., Evans, K., & Feltham, A. (2022). Participation at the Heart: Lessons From Child-Centred Practice in UK Healthcare During and Beyond COVID-19. *Establishing Child Centred Practice in a Changing World, Part A*, 61–75. <https://doi.org/10.1108/978-1-80117-406-020221005>
- BYC (2022) *NHS Youth Forum Reports 2023* London: British Youth Council
- Canas, E., Wathen, N., Berman, H., Reaume-Zimmer, P., & Iyer, S. N. (2021). Our roles are not at ease: The work of engaging a youth advisory council in a mental health services delivery organization. *Health Expectations*, 24(5), 1618–1625. <https://doi.org/10.1111/hex.13302>
- Cavet J, Sloper P. (2004) The participation of children and young people in decisions about UK service development. *Child Care Health Dev.* 2004 Nov;30(6):613-21. doi: 10.1111/j.1365-2214.2004.00470.x
- Children in Scotland (2019) *Meaningful Participation and Engagement of Children and Young People: Children in Scotland's Principles & Guidelines*. Edinburgh: Children in Scotland
- CLAHRC North Thames (2018) *CLAHRC Bite: Co-production in practice with young people in delivering a 'perfect' care pathway for diabetes* https://www.arc-nt.nihr.ac.uk/media/sckeqiyh/clahrc-bite-nhs_young_commissioners.pdf
- Coad, J., Flay, J., Aspinall, M., Bilverstone, B., Coxhead, E., & Hones, B. (2008). Evaluating the impact of involving young people in developing children's services in an acute hospital trust. *Journal of Clinical Nursing*, 17(23), 3115–3122. <https://doi.org/10.1111/j.1365-2702.2008.02634.x>
- Cody, C. (2023). Our Voices: What it's like working with – and being part of – youth advisory groups in the context of research focussing on adolescent health, gender and violence. Retrieved April 12, 2023, from <https://www.our-voices.org.uk/news/2023/what-its-like-working-with-and-being-part-of-youth-advisory-groups-in-the-context-of-research-focussing-on-adolescent-health-gender-and-violence>
- Collins, R., Notley, C., Clarke, T., Wilson, J., & Fowler, D. (2017). Participation in developing youth mental health services: “Cinderella service” to service re-design. *Journal of Public Mental Health*, 16(4), 159–168. <https://doi.org/10.1108/JPMH-04-2017-0016>
- Common Room North, & Association for Young People's Health. (2021). How to manage research and participation projects : Ethical considerations according to young people . Common Room North, (January). Retrieved from [https://irp-cdn.multiscreensite.com/29f8e96e/files/uploaded/Ethics in YP participation and research CommonRoom.pdf](https://irp-cdn.multiscreensite.com/29f8e96e/files/uploaded/Ethics%20in%20YP%20participation%20and%20research%20CommonRoom.pdf)

Davies S (2013) *Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays.*

Filipe, A., Renedo, A., & Marston, C. (2017). The co-production of what? Knowledge, values, and social relations in health care. *PLoS Biology*, 15(5), 1–6. <https://doi.org/10.1371/journal.pbio.2001403>

Hackett, C. L., Mulvale, G., & Miatello, A. (2018). Co-designing for quality: Creating a user-driven tool to improve quality in youth mental health services. *Health Expectations*, 21(6), 1013–1023. <https://doi.org/10.1111/hex.12694>

Hagell, A., & Beniche, S. (2022). *Engaging young people in health services research and service design: a new look at ethical issues.* London: Association for Young People's Health

Hart R (1992) *Children's participation: from tokenism to citizenship.* International Child Development Centre of the United Nations Children's Fund (UNICEF) Accessed 12 February 2022

International Association of Public Participation (2018) Spectrum of public participation. https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf

Lightfoot, J. and Sloper, P. (2002) 'Involving young people in health service development', Research Works, 2002-01, *Social Policy Research Unit*, University of York: York

Lundy L (2007) "'Voice' is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child", *British Educational Research Journal*, 33:6, 927-942, available at: <http://dx.doi.org/10.1080/01411920701657033>

Macauley, T., Rolker, H. B., Scherer, M., Brock, J., Savona, N., Helleve, A., & Knai, C. (2022). Youth participation in policy-making processes in the United Kingdom: a scoping review of the literature. *Journal of Community Practice*, 30(2), 203–224. <https://doi.org/10.1080/10705422.2022.2073308>

NELFT NHS Foundation Trust (2023) *Recommendations for effectively engaging with young people.* Retrieved from <https://www.nelft.nhs.uk/nelft-quality-improvement-news/recommendations-for-effectively-engaging-with-young-people-10481>

NHS England (2022) *Working in partnership with people and communities: Statutory guidance.* London: NHSE

NICE. (2021). Babies, children and young people's experience of healthcare. *National Institute for Health and Excellence*, (August). Retrieved from <https://www.nice.org.uk/guidance/ng204/chapter/Recommendations#consent-privacy-and-confidentiality>

NIHR (2021) Briefing notes for researchers – public involvement in NHS, health and social care research <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#briefing-note-seven-approaches-to-public-involvement-in-research>

Norton, M. J. (2021). Co-production within child and adolescent mental health: A systematic review. *International Journal of Environmental Research and Public Health*, 18(22). <https://doi.org/10.3390/ijerph182211897>

Ocloo J, Matthews R. (2016) From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf.* 25(8):626-32. doi: 10.1136/bmjqs-2015-004839.

Papoutsis C, Hargreaves D, Hagell A, Hounsoume N, Skirrow H, Muralidhara K, Colligan G, Vijayaraghavan S, Greenhalgh T, Finer S. (2022) *Group clinics for young adults living with diabetes in an ethnically diverse, socioeconomically deprived population: mixed-methods evaluation*. Southampton (UK): National Institute for Health and Care Research; PMID: 36063481.

Patient Experience Network. (2015). *Improving Patient Experience for Children and Young People*. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/sites/25/2015/03/pen-improv-patient-exp-cyp.pdf>

Picker Institute Europe (2015) *Recommending a Friends and Family Test (FFT) for Children and Young People* Oxford, UK: Picker Institute Europe

Picton-Howell Z (2020) Disabled young people's participation in end-of-life decisions. In L-M Brady (Ed) *Embedding young people's participation in health services: New approaches*. Bristol: Policy Press

RCPCH (2010) *Not just a phase: A guide to the participation of children and young people in health services*

RCPCH (2012) *Involving children and young people in health services – a report* London: RCPCH

RCPCH (2021) *Our vision for the future of paediatrics in the UK Executive summary*. London: RCPCH

RCPCH. (2023). *QI Module 3: Involving Children and Young People*. London: RCPCH

RCPCH&Us. (2017). *Educate, collaborate, engage and change*. London: RCPCH

RCPCH&Us. (2022, November). Epilepsy12 Youth Advocates. Retrieved from <https://www.rcpch.ac.uk/resources/epilepsy12-youth-advocates>

Reynolds, S., Fletcher, D., & Smith, L. (2021). *Virtual Youth Involvement Group – Communicating effectively and providing opportunities for young people*. Presentation retrieved from https://www.youtube.com/watch?v=6Me4fB73Odg&list=PL2OvEMhI_T9_SRbBit2AMM1nU6ddeMUXu&index=49

Richards, D. P., Poirer, S., Mohabir, V., Proulx, L., Robins, S., & Smith, J. (2023). Reflections on Patient Engagement by Patient Partners: How it can go wrong. *Pre Print*. <https://doi.org/10.7868/s0869565216240294>

Rouncefield-Swales, A., Harris, J., Carter, B., Bray, L., Bewley, T., & Martin, R. (2021). Children and young people's contributions to public involvement and engagement activities in health-related research: A scoping review. *PLoS ONE*, 16(6 June), 1–25. <https://doi.org/10.1371/journal.pone.0252774>

Street, C., Warner-Gale, F., Sedgewick, J., Roberson, J., & Anderson, Y. (2015). Taking on the Challenge: Shaping Health Services Through Young People's Participation. Retrieved from GIFT consortium.

Street C and Herts B (2005) *PUTTING PARTICIPATION INTO PRACTICE: A guide for practitioners working in services to promote the mental health and well-being of children and young people*. London: Young Minds

Thomas S, Clarke D (2015). Views of children, young people and families: the 15 steps challenge. *Nurs Child Young People*. 2015 Oct;27(8):16-9. <https://doi.org/10.7748/ncyp.27.8.16.s22>

Thomson A, Peasgood E, Robertson S. (2022) The Youth Patient and Public Involvement Café-A youth-led model for meaningful involvement with children and young people. *Health Expect.* 25(6):2893-2901.

Young Healthwatch Hillingdon (2019) *Hillingdon Sexual Health Services Review: Mystery shopping report*. London: Young Healthwatch Hillingdon

Van Schelven, F., Van Der Meulen, E., Kroeze, N., Ketelaar, M., & Boeije, H. (2020). Patient and public involvement of young people with a chronic condition: Lessons learned and practical tips from a large participatory program. *Research Involvement and Engagement*, 6(1), 1–13. <https://doi.org/10.1186/s40900-020-00234-1>

Watson, D., Mhlaba, M., Molelekeng, G., Chauke, T. A., Simao, S. C., Jenner, S., ... Barker, M. (2023). How do we best engage young people in decision-making about their health? A scoping review of deliberative priority setting methods. *International Journal for Equity in Health*, 22(1), 1–24. <https://doi.org/10.1186/s12939-022-01794-2>

Weil LG, Lemer C, Webb E, Hargreaves DS. (2015) The voices of children and young people in health: where are we now? *Arch Dis Child*. 100(10):915-7. doi: [10.1136/archdischild-2014-307492](https://doi.org/10.1136/archdischild-2014-307492)

West Yorkshire Health and Care Partnership (2022) *Partnership appoints non-executive independent members for new way of working* <https://www.wypartnership.co.uk/news-and-blog/news/partnership-appoints-non-executive-independent-members-new-way-working>

Westbrook, J., Allan, S., Gee, B., & Orchard, F. (2021) Reflections on running online expert advisory groups with young people with lived experience of depression. *Pre Print – PsyArXiv*, 0–3. Retrieved from <https://psyarxiv.com/m8ryh/>

Wheeler G, Mills N, Ankeny U, Howsley P, Bartlett C, Elphick H and Dimitri P (2022) Meaningful involvement of children and young people in health technology development, *Journal of Medical Engineering & Technology*, 46:6, 462-471, DOI: [10.1080/03091902.2022.2089252](https://doi.org/10.1080/03091902.2022.2089252)

Whiting L, Roberts S, Petty J, Meager G, Evans K. (2018) Work of the NHS England Youth Forum and its effect on health services. *Nurs Child Young People*. 30(4):34-40. doi: [10.7748/ncyp.2018.e1074](https://doi.org/10.7748/ncyp.2018.e1074).

Wittmeier K, Brown C, Diaz F, Pylypjuk H, Restall G, Anang P, Gerhold K. Collaborating with a Youth Council to Improve Chronic Pain Resources. *Can J Pain*. 2023 Sep 1;7(1):2254358. doi: [10.1080/24740527.2023.2254358](https://doi.org/10.1080/24740527.2023.2254358).



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For more information

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