Engaging young people in NHS service delivery and development

Results from a sector survey and interviews

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Executive summary

Despite considerable and growing support for public and patient participation with young people in the development and delivery of health services, what is actually being done in practice across the country is not widely known or shared.

In order to present an overview of current practice we undertook a scoping exercise, including a survey and interviews. The overall picture was positive, in that there is clear ambition and commitment to broadening the participation of young people in health services design and delivery, and many examples of work ongoing. There is consensus on the essential building blocks, and the challenges and barriers.

However, the work is sketchy, patchy, and happening in silos. The extent to which individual attempts are successful, enduring and meaningful varies hugely and many fail for lack of resources and staff capacity or skills. The work is often under recognised and under resourced.

There is clearly room for guidance across the health system to help people decide what kind of participation work is feasible and appropriate for them, and to provide some pointers to good practice.

Introduction

While patient participation is widely seen as an important and valuable contribution to the development of healthcare services, we do not have a good, post-pandemic, overview of current practice in relation to young people. This report outlines the findings from a survey of people undertaking youth engagement and participation in health service design and development, combined with the results from a set of more detailed interviews. This complements our separate paper on findings from a review of the evidence base including published papers and reports, which sets out more fully the reasons why engaging young people is important, and a separate set of recommendations. The work was funded by the NHS England Children and Young People's Transformation Programme.

The aim was to get a snapshot of the different ways that young people currently participate in health service developments, to explore the range of activities that fall under this heading, and to unpack some of the enabling factors and barriers that practitioners may be facing in developing this work. It is intended that both this account of practice, and our separate review of publications and reports, can inform the development of good practice.

Methods

The Association for Young People's Health (AYPH) designed and circulated a short survey of ten questions using Microsoft Forms. It was presented as a quick survey of young people's participation happening within NHS structures in different parts of England. We defined participation as working with young people to actively include them in decision making about health service improvements.

Questions covered the following topics:

- The kind of organisation respondents worked in (e.g. NHS trust, Primary Care Network (PCN), Integrated Care Board (ICB), mental health trust, hospital, community health service)
- The extent to which the organisation (NHS trust, PCN, ICB, mental health trust etc) involved young people in service development, delivery and/or evaluation, and the methods used
- The types of staff involved in supporting and facilitating participation activity
- How participation work is funded
- The barriers and challenges faced in embedding young people's participation in service development, delivery and/or evaluation, and any lessons learned

Some of the questions included open-ended response categories for respondents to contribute free-flowing text. The survey was complemented by a set of nine semi-structured one-to-one interviews with clinicians and others involved in youth participation work in the NHS including a paediatrician working in a hospital with no structured youth participation, clinicians working with new or one-off groups of young people, and a young person experienced at being a youth board member. The interviews took approximately 20-30 minutes and covered respondents' experience of youth participation in the NHS, what enabled them to do the work, what the barriers might be, and their experience of measuring outcomes and quality in youth participation work.

The project did not need NHS ethics approval as it fell under service improvement/evaluation (https://www.hra-decisiontools.org.uk/ethics/). However, it was undertaken in accordance with AYPH policies (safeguarding, consent, working with young people, and GDPR).

There was a total of 39 responses to the survey. The responses were collated into a large excel spreadsheet, and analysed thematically (originally by LMB, separately and secondarily by AH, and then subject to project team discussion). The nine interviews were transcribed and also subject to thematic analysis. The results section below combines the themes arising from the two different methods.

A word on terminology. In different sectors the terms 'engagement' 'participation' and 'involvement' can have different meanings. While we intend them all – in this context – to mean aspects of involving young people in service design and delivery, they can also sometimes be used in the health sector to mean the extent to which individual patients are taking part in services – the extent to which they are engaged in their own care and turn up to appointments. Where this turned out to be an issue we redirected attention back to the construct we were interested in, if necessary using language that worked better for respondents.

Survey respondents

Respondents came from a wide range of contexts, including a variety of NHS Trusts around the country (Foundation Trusts, Hospital Trusts, University Trusts and Integrated Trusts), different kinds of community health services (including at least one 0-19 service), ICBs, specialist services (such as a paediatric sexual assault referral centre, and a youth-specific GP service), CAMHS, and specialist community nursing teams.

Respondents were asked which staff were involved in supporting the youth participation they were describing. The most common response was some variation on youth voice leads, participation leads, involvement leads and specialist participation teams or co-production leads, but the list also included all of the following plus more:

- Health and wellbeing staff
- Clinical academic staff
- Consultants and junior doctors
- Non-clinical hospital staff
- Psychologists and counsellors
- Physiotherapists
- Youth workers
- Social care staff
- Nurses (hospital nurses, school nurses, community nurses)
- Health visitors
- Managers, directors and commissioners of services
- Crisis workers
- Arts facilitators and play therapists
- Social prescribing link workers
- Digital pathways leads
- Research assistants and associates, PhD students
- Transition leads
- Dieticians
- Volunteers

Current practice: approaches to participation

It is clear that a wide range of activities currently take place across the NHS health service and beyond that fall under the heading 'youth participation or engagement'. These can be plotted against standard frameworks for describing patient participation; Figure 1 plots examples from the survey and interviews against one such framework proposed by the International Association for Public Participation.

FIGURE 1: The range of ways in which young people are engaged in health service design and development

Level of participation	Examples from survey and interviews
Inform	• Preparing young people for what might be discussed in consultation sessions • Talks to schools/youth groups about health services and how to engage
Consult	• Feedback questionnaires • Service 'engagement days' • Clinic chats (talking to young people in clinics about how the experience is for them)
Involve	• NHS Youth Forum • Hospital youth forums • Service specific advisory groups • Project specific advisory groups • Individual youth advisors for services • 'Secret shoppers'/'secret agents'
Collaborate	• Peer researchers • Co-design of new services
Empower	• Shared leadership (such as representation on NHS forums)

Other important dimensions are not reflected in this kind of framework.

These include:

- The distinction between engaging with one young person – a youth advisor of some kind, or a young Trustee – versus involving a group of young people.
- The difference between engaging by bringing young people into a service, versus going to young people in their own spaces.
- The distinction between involving generic or general groups of young people (such as those in a local youth group) versus targeting young people with particular lived experience (such as cancer patients, for commenting on cancer services).
- The difference between having a standing group of young people who are tasked with general consultancy, versus specially convened (or time limited) groups for specific services or tasks.
- The slightly different distinction between drawing on specially convened groups of young people, versus using already established groups and going to them, or asking already established groups for volunteers to make a temporary single project group.
- The distinction between having certain structures in place (youth forums) versus what actually takes place in the meetings, which might be a range of rather different kinds of activities
- And finally, the distinction between whether participation is face-to-face or virtual is important, which is an important consideration post-pandemic. Remote participation is more common than it used to be and brings particular challenges, while also potentially making sessions more accessible for some groups who find attending face-to-face is a challenge.

This brief overview demonstrates the complexity at work here. All these methods are important in one way or another, and all will be suitable for some purposes and not for others. Finding the right kind of participation for the purpose is a key part of the challenge. There will be no overall 'best' way of doing this; the task requires consideration and skill to fit the method to the aim.

This was not intended to be a comprehensive survey of what was and was not happening across the whole sector, as we asked for examples rather than taking a representative sample and asking whether they were involved in participation or not. We cannot estimate how many services and hospitals do or do not involve young people, but the reality is likely to be that lots do, in very many different and ad hoc ways and to varying degrees of success, but also that many do not, for lack of expertise and funding. In addition, practice varies within institutions; one department may have advanced ways to consult with young people, others in the same hospital, for example, may do no participation at all.

Requirements for successful participation

In both the survey and the interviews respondents were asked about what made for successful participation. Responses were very consistent and can be classified into six main groups: clarity of aim, practicalities, capacity and skill, structure and leadership, investment, and reflection.

Clarity of aim

As a fundamental starting point, respondents emphasised that successful participation with young people needed to start from a position of clarity about the aims of the participation. This needs to be built on a clear and shared definition of what 'participation' means and what it looks like in practice, and also requires honesty about what can and cannot be changed. Participants need to be clear about the extent to which they are actually willing to share power and let young people lead, and should explore and acknowledge the power and control issues before the participation begins. Full power does not need to be shared for successful participation, but if participation is only to take place at the level of, for example, 'consulting', then everyone should be clear on this at the outset. If this is not addressed, as one clinical manager noted, *"….sometimes it can just become a bit like white noise, can't it, the word participation. The asking for the voice stuff. And it's actually harder, the how we make it, how we make a difference with it [a] bit, I think."*

Respondents often referred to the importance of participation being as meaningful as possible, and *"….not just viewed as a way of backing up what is already ongoing or supporting things that people already want to do."* As one noted, *"The aim needs to include an openness to being challenged and a readiness to respond to that."*

Clarity has to be achieved through communication. This is both within the service and also with the young people, thus *"So I just think it's about having the right support around them, being really clear about what their role is and then really talking to other people on the board so that everybody understands what their role is."*

Clarity is also needed about the appropriate kind of exercise to undertake. Respondents suggested that *"you need to think about what is the ideal participation structure with young people for your organization at this time, and what is realistic and have a really clear plan for how you're going to develop that in a way that's sustainable."*

Addressing practicalities

Respondents raised a number of practicalities around undertaking participation that need to be considered for successful outcomes.

This is not a definitive or exhaustive list, but examples included:

- Devising activities that are appropriate, creative, fun and exciting
- Working in ways that are flexible and suit other demands on young people's time
- Considering a range of options for participation rather than a one-size-fits-all; thus as one young person said, *"You have the constant members, who attend the first Monday of every month. But you'd also have those members that drop in and out, who have the fascination with the bits like CAMHS. And I think that flexibility throughout a young person's life is very important."*

- Doing sufficient advance planning, and allowing resource for this
- Considering how to reward and recognise the young people involved
- Considering appropriate physical spaces for participation, both for the actual event but also for preparation and debriefing. This includes safe and private spaces for those engaging online. Some ways of making these spaces may involve, for example, making parallel, private WhatsApp groups alongside online participation, for ongoing conversation.
- Sorting safeguarding. There was a considerable amount of commentary on this in responses, and it clearly poses a challenge, so it is a key practical consideration. Existing service level safeguarding may need revising or adapting to ensure participation is safe for young people and workers, including for example, internal systems for risk assessment and consent.
- Arranging practical access. This includes enabling young people to get to meetings, attention to special needs they may have to facilitate participation (palantypists etc), and suitable timings that fit around the school and work day.
- Finally, an essential practicality involved how to recruit young people in the first place, and we return below to the importance of partnerships with other organisations who are already supporting young people and have trained staff.

Capacity and skill

The capacity and skill required to lead and manage participation was probably the dominant theme across the survey and the interviews. It cropped up in a number of different ways in response to different headings. It included issues of time (in terms of capacity), space in professional roles to take on the task, and need for particular skills to ensure meaningful, safe and impactful participation.

Respondents commented on the pre-existing time pressures on staff, and the need for the acknowledgement of the effort that participation can – should – take. As a community co-production lead and clinical manager in the South of England commented, *"You know, there is at times pressure on our clinical staff to make sure they're doing their mandatory role first. Not that anybody doesn't think co-production is important, but there is an element. You have to also respect that there's certain elements of the service from a clinical point of view that has to take place…so it's about also realizing sometimes it can be about human resources and availability"*.

Requests for there to be participation could sometimes be made without understanding of the size of the task, as in *"[She] sometimes comes and says, can you get this by next week? And I'm going, no, no, I can't because you may be asking me to contact a group of people I don't have a relationship with yet. And actually that takes time to build that up. Yeah. So time is key for co-production, full stop. Time is key."*

Even the planning needs sufficient time, and this needs acknowledging. As one youth engagement leader said, *"So they've been involved in a project like that, but not a lot of work has been done, if I'm honest with you, because of the process of even the plans. And then I've had to develop a safeguarding policy to deliver that. And then that had to go through governance and impact equality assessments. There's a lot of red tape before you can actually get some work done. Which I'm not used to because I'm coming from a local authority."* Negotiating agendas, writing minutes, and communicating outcomes all require time over and above the actual participation exercise.

Others noted the need for time to build trusted relationships and rapport between staff and young people, time to prepare young people and carers for what to expect in the session, time to discuss, reflect and allow new project and ideas to flow, and time to organise meetings with other professionals to act on the session findings.

And of course the young people need time and capacity too. Many will be fitting participation around demanding daily lives, or the management of complex health conditions. They will need time for reading and understanding what will be discussed, time to get to and from meetings, and time for spin-off discussions.

The specific skills necessary to lead participation work was a key part of the conversation around having sufficient capacity. For good participation, highly skilled staff are a pre-requisite. We return to this in the section on barriers below.

Structure and leadership

Another frequently mentioned pre-requisite for engaging young people was the presence of appropriate structures and senior leadership. Ideally, participation takes place in a system where it is embedded throughout, rather than being an isolated activity. Ideally it is supported at all levels within service providers, including staff, managers and commissioners. Sometimes this leadership includes youth leadership, in that young people may be represented at Board level.

Many respondents noted how important this was. As one trainee paediatrician commented, *"I think having a really supportive consultant has helped."*

Financial investment

In addition to the time element, there is a growing acknowledgement of the amount of financial investment that engaging with young people may require. As one consultant commented, *"… like anything, if you want it to happen and happen well, then you need to dedicate time and resources to it and that's a really big barrier, that it's not seen as a priority and therefore time and resources aren't put towards it"*. Others commented that being overt and realistic about the investment is key to long term sustainability.

Reflection

Building reflection into the process was seen as key to good participation. This was both reflection on the part of the staff and systems involved, and also facilitating the young people to reflect.

Respondents also noted that being part of participation led to reflections about its importance and value. Thus, as one suggested *"…..I think it's a really important thing and I'd never really, I guess despite being the sort of person that would always have been open to it, I don't think I ever saw just how important it was until I got involved with it. And I think having the opportunity to be involved with it a lot earlier maybe would've pushed me to do some more stuff with that council."*

A young person added *"Go to an engagement event and find it. So it is about really positive experiences. And seeing them, seeing the value. And then the workers are like, oh yeah, we really need to do this more. So when you've had a really positive experience and it's been a really successfully thought through event, then I think that helps people to see."*

Barriers and challenges

Inevitably the barriers and challenges that respondents identified often reflected an absence of the key features necessary for successful participation.

A lack of understanding about the aims and importance of the work could lead to a 'tick box' approach, as one youth engagement leader in the South of England commented: *"…there is some people who are: we don't do it like this. This is what we've gotta do. You know, get some consultation, just feed it back in, it's a tick box exercise. And a lot of participation, which I found out across the system is a lot of tick box exercises. You know, as long as it's done and we can say it's done, its fine. But it's not really meaningful. And I think when you're trying to engage with young people, parents, carers, families, whoever it is, a patient, that if they feel used or feel like it's not genuine, you're not gonna get 'em back. So I think that's one part of it. As another noted, "… the young people put in their effort and then it come to nothing because somebody at exec level just overrides it. And I can see that happening unfortunately."* Overall, in terms of willingness to share power, we found very few examples of young people actually being involved in co-design, co-production and strategic decision-making.

A **lack of leadership and investment** is a challenge. This can relate to the perception that participation is an additional demand on the workload. Thus, as one respondent said, *"I think getting some of the senior management team on board has been a bit of a challenge. I think partly because we're asking them to do more stuff. So that's obviously always a bit tricky."* This is shortsighted, as another commented: *"I think it's a slow burner. It's a statutory duty, but I think if people can put that at the bottom of the list, they'll literally put that at the bottom [of the] list so they can crack on with other stuff. I think they're missing the point around participation. If you do it in an earlier enough stage, then you ain't gonna have that problem of, oh, this service is not working because we've booked an appointment in the middle of a school day."* It can also be difficult to change deeply entrenched ways of working.

Lack of understanding of the skills needed is clearly an issue, and clearly a related to the discussion above about capacity and skills. Culture clash between disciplines could also be an issue – for example, the overlap with youth work: *"So the leadership are supportive, as much as they understand about youth work. So that's probably the best way to put it. And across the organisation the support is there for as much as they understand what youth work is. So some of the leaders and some of the professionals don't understand youth work. So it can appear that they're unsupportive, but then you can only go as far as you understand."*

A major issue raised as a barrier was **the difficulty of achieving appropriate representation** among the young people. Many respondents commented on this. Sometimes the easiest young people to engage may not represent the core group that you need to reach; *"I think one of the limitations is the kind of composition of that group. So it was mainly there were some long term patients, but there were a few that were kind of interested in going to medical school, so didn't have a lot of health experience of being a patient in the healthcare system. It was still very valuable. But I wouldn't say it was the most representative sample of our population that we serve."* Relying on the same young people again and again also narrowed representation. As one respondent said, *"In terms of getting your wider voice, sometimes you've got to dig a bit deeper"*.

One of the solutions to this was to ensure the participation staff represented the young people's own experience, so that, for example, *"What I noticed was that we spoke a lot more to those from ethnic minority backgrounds and their experiences and the reasons that they couldn't join was very different from those that have joined. So it's about us thinking about that and how we can navigate that to try and include them more. And also I do find personally, being from an ethnic minority background myself, that cultural differences exist."*

Another challenge related to the **management of people's expectations about what the young people were there to do**. One expert in youth participation commented on this saying *"…the other thing that often happens is that young people are contacted outside of a youth forum meeting by another member of the board, do another piece of work. Now, that might be completely fine, but actually it might mean that they end up feeling that they can't say no. And there's too many things that they're having to manage and deal with."* Managing duplication of requests and over-consultation is a part of this.

Understanding young people's life stage and priorities can also be a challenge. Keeping young people engaged can be difficult, particularly if they are going through exams and educational transitions. It is not unusual to start a participation project with lots of enthusiasm and a fairly large group, for this to fall away quickly after a few meetings. In addition, young people inevitably move on fairly swiftly and systems need to accommodate this rather than viewing it as a problem. A clinical manager in the South of England commented: *"So I guess for the young people, that's the biggest element of it, is we have a constant changeover. Not because we've chosen to go somewhere else, but because their buy-in is – I've done my bit actually, I'm busy doing this now."*

There are challenges around the need for more communication, which interrupts efficiency – within hospitals and systems, but also across the piece. *"We've discovered all of our physios, OTs, everyone else sit under an organisation called XXX, and they've got an entire Young People's Engagement Forum. The paediatricians just didn't know about at all, completely unaware of it, but they have apparently been feeding back loads of health data, which hasn't been passed over to us. So it's a matter of finding out what's out there and tapping into it and then saying, oh, okay, actually all of this is really useful".*

There is also a **lack of investment in measuring impact** across all youth participation in health services design and delivery. As our parallel literature review showed, there have been very few attempts to seriously measure what difference participation makes and what the ideal conditions for it to flourish might be. At a more basic level there is a shortfall in outputs that simply describe what has been done for wider audiences; often knowledge is kept within the team and lost when people move on.

Finally, there the **challenge of responding to varied needs and preferences**. Some young people will be suited to some kinds of participation and others to different types, and they cannot all contribute to all topics equally. As one respondent told us, *"I think it's probably also remembering that these kind of roles are not going to be for all young people. One of the dangers, I think is you get eight young people, "oh, we've got young people, we'll ask them". Well, we can ask them about a lot of things and they'll have a lot of things to bring. But if you ask them about obesity and none of them have had any personal experience of it, that's not appropriate."*

Opportunities

Despite the challenges and barriers, the current situation in youth participation in health services design and development presents clear opportunities. There is no doubt that there is an increasing interest in co-production and co-design – so that *"everybody's really into it, because obviously they can see the impacts of children and young people within the service, services, primary care, whatever it is, that's a good part of it and joined up working is really key."*

There is a growing understanding of the opportunities offered by working in partnership with voluntary sector, local authorities and other organisations to involve diverse young people and to draw on their experience with participation. One community co-production lead illustrated how this might work when she said *"…actually by going out to those groups that are established, whatever it is as, as [name] said, we've gone to schools, we've had St. John's Cadets, we've had Youth in Mind, we've had YABS and, and SEND Youth Forum that we've gone to. They already have people working and supporting them that trust them. So we're not having to spend that time building that relationship up". There were frequent comments on this from other respondents, including one who said "I think there's definitely more advantage to think about how you can partner with local organisations, local schools, local youth organisations, [instead of] this sense that we've got to directly recruit our own youth panel."*

There are also opportunities presented to have a more explicit conversation about how to balance the needs and constraints of the system with the needs and perspectives of young people – leading to true co-production – *"Because it can't all be about young people going, we want this and then we want this, and then we want this, and then we want this. Because that's unrealistic, but neither can it be about organisations going, no, no, no, no. We're just going to do what we want, so there's got to be more room for manoeuvre and flexibility on both sides, I think."*

Opportunities for innovation are also developing as the participation work becomes more common – *"We also need to be better at getting more innovative ways to get those voices directly to the people who can make a difference and change things." "It's like, you know, when people who advise you on how to have difficult conversations with your child, it should be like in the car when you're not looking directly at each other."* This can involve thinking of new ways to engage people that perhaps does not even require them to speak (*"Actually, I don't want to speak out loud at all. I want to just communicate via a message or typing that doesn't require me to speak out loud."*), and opportunities offered by the use of social media and online tools and platforms.

And there are opportunities for more research on the uses and impact of participation with young people.

Finally, a number of respondents requested more resources and outputs from NHS England to support this work. This included, for example, *"If NHS England wanted to do one thing, I think supporting youth workers to get embedded into paediatric services would be a huge boon and I think you'd be able to reap multiple rewards from that.", and "I think getting in there early*

and getting paediatric trainees trained on this sort of thing as well, I think all of that would be really valuable." More information on how to advocate for this was requested; *"….there needs to be a chapter on how do you make the people at the top listen. And make sure that what you are receiving is impactful and that change is made."*

One organisation shared that *"We're building a library where professionals can access it and get examples of co-production, have contacts, if somebody wanted to do something similar to what we've been doing. They will have what we've done and they can contact us as an organisation or me as co-production and say, I'm gonna do something similar, don't wanna duplicate and what's the best way to do things. So it is happening".*

Conclusion

The picture from this scoping exercise was positive, in that there is a clear ambition and commitment to broadening the participation of young people in health services design and development. There are many examples of work ongoing, and lots of lessons already learned. There is consensus on the essential building blocks and the challenges and barriers.

However, the work is sketchy, patchy, and happening in silos. The extent to which individual attempts are successful, enduring and meaningful varies hugely and many fail for lack of resources, staff capacity or skills. Successes often rely on particular passionate staff who are willing to put in the extra effort to make it happen. This does not lead to sustainable frameworks for ongoing work. This is complicated by the ever-changing and transitional nature of young people's lives; systems need to be sustainable in the face of constant change. It is not enough to find a few willing young people and ask them to comment on everything for several years in a row. Yet this clearly does happen (*"What I've seen plenty of is participation or co-production done badly"*). Even some huge and important structures have yet to face the challenge (*"So I've gone into the ICB. And then I've realised oh, they don't really have the voice of children and young people at all across any sort of platform within the ICB. So that was quite a shock, it being such a huge health establishment, obviously with NHS England"*).

Given AYPH's extensive experience in youth engagement across the health sector, we were also struck by some of the things that were given less weight in responses to this project. In other work we have noted issues around the power tensions that can sometimes arise in using youth workers to deliver participation work with young people. Despite high levels of skills around participation, youth workers can lack the power to advocate for young peoples' needs within the clinical system, reducing the impact of the work. We were interested this was not raised, but the ongoing pilots on using youth work to facilitate participation of this age group in health services may provide additional useful information about how the role is operationalised. We were struck generally by how few respondents discussed co-production work, and as we have noted, this may be because it comes with more demands, again around power sharing. Finally, the lack of robust evaluation (particularly in relation to possible harm and the ethics of participation work) is notable.

Overall, there is clearly room for guidance across the health system to help people decide what kind of participation work is feasible and appropriate for them. The importance of this being well-resourced and undertaken by people who are trained to work with young people cannot be underestimated. An overarching message was that there was no one-size-fits-all, and that people may need support in thinking about the right kind of participation for the task at hand.

We end with a realistic, positive quotation about the importance of simply starting the work and working with what you have available; *"I think it's starting with what you've got. What I mean by that is it doesn't have to be this whole all big singing and dancing youth forum. Start with a group of young people that you've got, because I think meeting them where they're at is so important."*

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For more information

For more information about this project,
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