Engaging young people in health services research and service design:

Key constructs and ethical challenges

Scoping the evidence

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In brief

In recent years young people have begun to play a larger role in health services research and design. Their views are sought and valued, and expectations around user engagement have substantially evolved. As well as taking part in research in traditional ways, governed by university research ethics procedures, they are also involved in co-production, co-design, advisory roles and dissemination. University research ethics applies to some of this activity, but not all. Other, different frameworks shape some kinds of ethical engagement practice, but some participation activities fall between stools.

In this scoping review we differentiate and map the range of ways in which the sector is involving young people in health service research and development, identify key concepts and definitions in the literature and highlight governance issues and contradictions arising from the range of approaches.

We conclude that it is critical to move beyond viewing ethics approval as something that researchers have to 'get through' before projects can start, so that ethics can be extended to the more iterative and dynamic ways of involving young people in our work that are now being employed. It is also critical that appropriate levels of ethical scrutiny are applied to all the different kinds of engagement we undertake, not just that falling into traditional research categories. Some general principles of ethical engagement could potentially underlie all this activity, but it is also likely that different kinds of engagement require some tailored guidelines.

Background

Young people have played a significant and important part in research for decades. The majority of this has fallen into traditional research categories; qualitative interviews; quantitative surveys; longitudinal studies; observational studies, and other methodologies. In addition to these traditional ways of involving them in research, more recently there has been an explosion of interest in extending how we engage with young people in more flexible ways over and above simply relying on them as research subjects. Within the research world this has included, for example, involving young people in setting the research agenda, helping to identify research topics, sitting on research advisory groups, working as peer researchers and responding to and disseminating results.

Beyond research, though, is a whole other world which is also alive with activity. Young people are now involved in co-designing and co-producing new health services targeting their age group, advising policy locally, nationally and regionally, fronting health campaigns and generally becoming partners in all aspects of the work done to improve youth health (Brady, 2020). The importance of facilitating youth voice, youth engagement and patient and public participation have meant this is a growth area (Lancet Child and Adolescent Health, 2021). This reflects a fairly longstanding and increasing interest in involving the community in service development (eg, Bovairt, 2007).

The Association for Young People's Health has feet in both the research and the service development camps. And indeed in the policy camp too. As such we have been involved over recent years in a wide range of ways of engaging with young people within the 10-25 year age range. At its core, our work rests on young people's rights in health, including their right to be heard (UN General Assembly, 1989). Over time we have become interested in how differently their rights and the underlying power dynamics between them and professionals play out in different research and participation activities. We have also begun to wonder what young people think about it all.

Formally, this is called ethics. Yet the way in which we approach ethics in relation to young people's participation varies hugely depending on what kind of activity they are engaged in, and which disciplinary framework professionals have been trained in. In addition, the ethical frameworks employed often have their historical roots in models of research where harm might be quite likely, such as medical drugs trials (University of Nevada, 2021), which has led to a framing of ethics as being mainly about risk, rather than about rights. Indeed, current UK Economic and Social Research Council research ethics guidance states "The principal ethics consideration should be to ensure the maximum benefit of the research whilst minimising the risk of actual or potential harm." (ESRC, 2015) Over the years we have presented our research protocols to formal ethics committees, and we have undertaken a lot of work that did not require any external ethical scrutiny. The rationale for following one route rather than another is not always entirely clear and may not be based on what is best for young people but more on the checks and procedures required by institutions.

However, if you are a young person, facing a confident professional with a computer, clipboard or interactive exercise, it may be immaterial to you whether this is a piece of research, co-production or engagement. You may not know the difference, and it may make no difference to the risks you face or how you feel about it. But young people always have rights, even if they are not fully aware of them. We were interested in the spectrum of ways in which we are engaging young people, and the extent to which different activities could share an underlying ethical framework, or whether some activities needed different approaches. We wanted to bring clarity to the issues of ethical engagement with young people in all its forms, and clarify knowledge and practice gaps.

We define engagement as involving young people in activities, planning and making decisions that affect themselves and others. Recognising that children and young people are experts in their own lives is vital to ensuring that their voices influence research, policy and practice, and inform service developments. This includes the voices of young people who typically face barriers to being involved in engagement activities. In addition, there is little doubt that public involvement improves research and service development (Evans et al, 2014). The benefits, however, are not restricted to research, and extend to all sorts of engagement.

This project, funded by the Nuffield Foundation, has had two components. In this paper we present the results of an exploratory scope of the evidence. This was not intended to be a formal scoping review, but we did want to do some of the initial ground clearing and to clarify the issues and key questions. Alongside this we also partnered with Common Room, a youth engagement consultancy, to talk to young people about their experiences of being involved in health research and service development. A separate report from Common Room is available from their website. We have also published an AYPH briefing paper for the project, which brings the two pieces together and starts to set out next steps.

We have restricted the focus of this scoping review to health services research as this is a way of providing some clarity and boundaries to this element of the project. By this we mean how people get access to health care and what happens to patients as a result of this care. However, the report from Common Room and associated stakeholder conversations demonstrate that the implications of this project will be much broader.

Aims of the scoping exercise

The aims of the scoping exercise were to:

- Differentiate and map the full range of approaches to involving young people in health service research and development
- Identify key concepts and definitions in the literature in relation to engagement and ethics
- Outline emerging issues and contradictions
- Identify knowledge gaps and frame the questions that still need answering
- Identify the types of existing ethics frameworks that already exist for qualitative and quantitative research and assess the extent to which they can meet the needs identified

Methods

As the purpose was to identify knowledge gaps, clarify issues and scope the literature, we undertook an initial mapping exercise, rather than a systematic review. We knew at the outset that the relevant literature was likely to be disparate and disconnected, with some relevant pieces not formally published. The intention was that this scoping exercise could potentially become the precursor to a systematic review, but at this stage the important thing was to bring clarity to the questions and set out where relevant literature existed.

Studies were found using Google Scholar and PubMed, as well as from reference lists and citations. Search terms such as 'research', 'engagement' 'participation' 'co-production', 'children and young people' and 'ethics' and 'ethical practice' were used. Not all included papers were specifically about children and young people, if they were relevant to the exploration of key concepts and definitions. Published and grey literature were included, as well as guidelines and case studies. The search was not geographically limited but the majority of papers included came from the UK and northern Europe.

Parallel work with young people informed the approach. As part of the project. between October and November 2020, Common Room North engaged 20 young people in interviews exploring ethical considerations when involving young people in participation, research, and co-production. There was a rich diversity of interviewees in relation to their individual experience of involvement in research or participation projects as well as their age, location, ethnicity, sexual identity, faith, and disability. The report from the engagement work is available from Common Room. The issues and questions raised by the young people informed the search strategy and the remit of the scoping review.

Findings

Our scope of the existing literature helped us to clarify the range of ways in which we engage with young people in health services research and service development, consider some of the key constructs, identify some existing ethical guidance and frameworks, and pull out key issues and contradictions.

(1) Ways of involving young people in health services research and service development

We are interested in engagement with young people across a whole spectrum of activity, from formal randomised control trials to occasional participation at, for example, publication launches. All these kinds of activities are for different purposes. Engagement may also be undertaken in a range of ways within any one of those categories. In formal research, for example, as well as being research subjects young people may be involved in advisory boards, discussion groups and report dissemination. The extent of engagement and type of approach taken will be determined according to the nature of the specific research project or activity, the available resources and the preferences of the children and

young people concerned. Understanding exactly what it is we are asking young people to do is critical to understanding the ethical considerations.

Our scoping exercise revealed a wide range of different ways of involving young people in health services research and development. For example, the National Institute for Health (NIHR) has set these out in a 'research cycle' including identifying and prioritising topics, commissioning and funding projects, designing and managing the work, disseminating and implementing the findings. People may be actively involved in the research process itself, or they may be participants or subjects of the research. Some of these activities are traditional research activities, but others are classified as "patient and public involvement" (NIHR, 2021a). The public may also get involved in advising about new services, without any research element.

Figure 1: NIHR research cycle

Adapted from NIHR (2021)
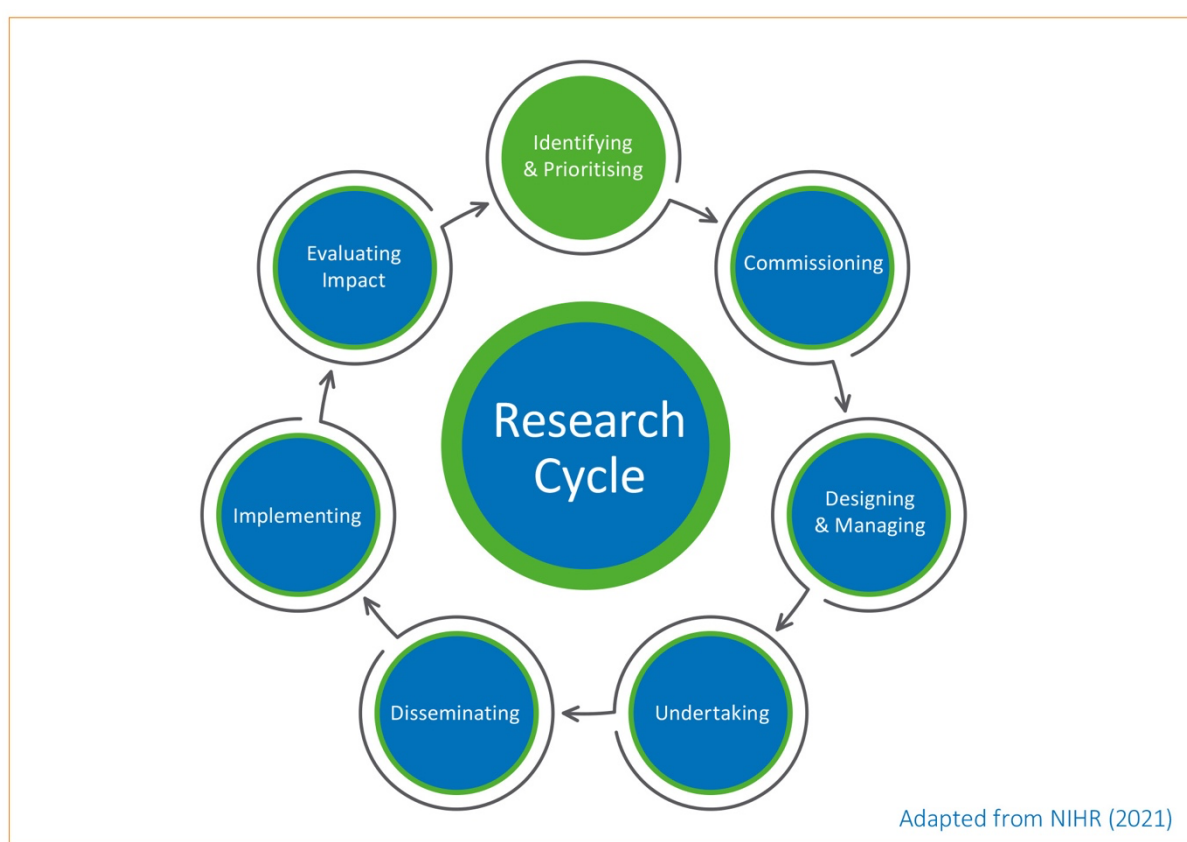
Looking specifically at taking part in research studies, involvement in the broader research process, engagement in planning new services, and involvement in policy and advocacy, these are some illustrative examples of youth engagement that we have come across:

Taking part in research studies

- Young cancer patients as participants in a randomised control trial of a new treatment (Braam et al, 2018)
- Young people completing health behaviour surveys as part of a large school based study (Brooks et al, 2020)

- Young people involved in participatory action research on domestic violence Matthew et al (2019)
- Peer researchers, reaching out to their friends and acquaintances to complete surveys co-designed with professionals (Hagell and Rigby, 2018)

Involvement in the broader research process

- Young people advising on research design (eg, Alpha Group, DECIPHer, Cardiff; DECIPHer 2021)
- Young people working with practitioners to design outputs summarising the results of studies (Association for Young People's Health, 2018)

Engagement in planning new services

- Small focus groups of young people to discuss the introduction of new interventions (James et al, 2019)
- Young people providing detailed case studies of their lived experience (Transition to Adulthood, 2021)
- Young people involved in formal co-design of new services (Association for Young People's Health and the TOGETHER project team, 2020)
- Young people chairing meetings of policy and practitioner stakeholders Greater Manchester Combined Authority, 2020)

Involvement in policy and advocacy

- Young Trustees on health charities (Young Trustees Movement, 2021)
- Young people with governance roles within the NHS, for example the Children and Young People's Transformation Board (NHS England, 2021)
- Young people helping to present the findings of projects to policy makers and wider audiences (Imperial College London, 2020)
- Young people on advisory panels and forums, such as the NHS Youth Forum (British Youth Council, 2021)
- Young people training as 'Health Champions' (Royal Society for Public Health, 2021)

There are standard ways of conceptualising the level of engagement that participants can have in the development of research projects or new services. For example, an early and widely used framework was called the 'ladder of engagement' (Arnstein, 1969). *Figure 1* presents a very simplified continuum as usually represented in these kinds of models, ranging from low levels of engagement that essentially just keep participants informed, to high levels of engagement that include shared power in, for example, making decisions about research aims and methods, or next steps (IAP2, 2014).

*Figure 2: A spectrum of public engagement (adapted from IAP2, 2014)*
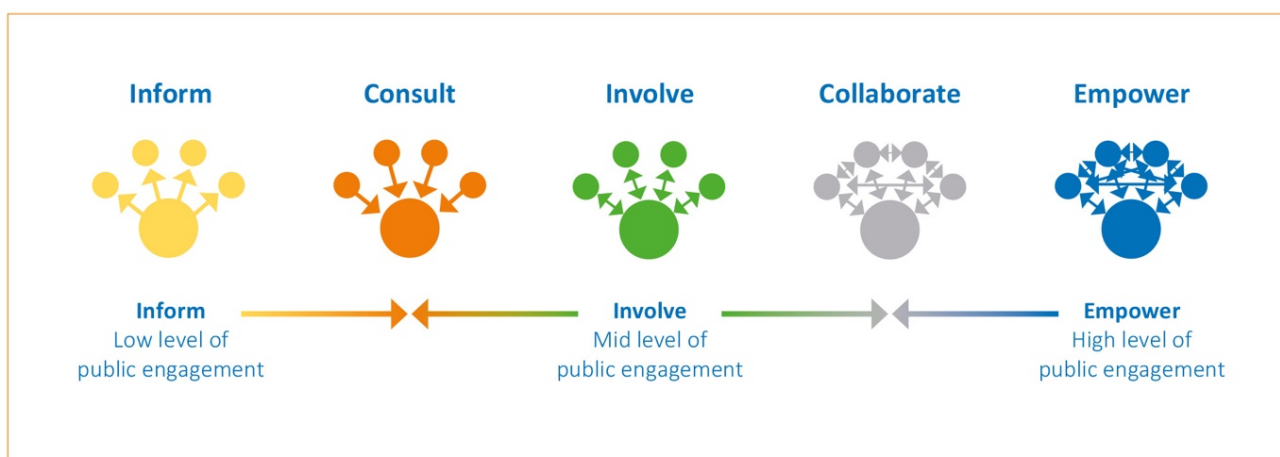
The improvement agency Social Care Institute for Excellence (SCIE) has a widely cited model that is very similar in construction, differentiating between engagement through input, contribution, or shared control (SCIE, 2021). Others sharing similarities include the Ladder of Children's Participation (Hart, 1992), the Youth Engagement Continuum (Funder's Collaboration on Youth Organising, 2003), and the Typology of Youth Participation and Empowerment Pyramid (Wong et al, 2010) among others.

As we have suggested, various different kinds of activities such as research and service development might engage young people to a different extent. In *Figure 2* we have set this engagement continuum against a range of possible research and service planning activities; effectively mapping different kinds of engagement against different levels of engagement. This illustrates the wide range of ways and levels of engagement that happen across the piece. It demonstrates that simply because something is, for example, 'research', the extent to which it might engage young people can vary. Some aspects of research may only meet the 'inform' levels; other aspects might go so far as to 'empower'. Similarly with, for example, service design; elements of this might simply 'inform'; others might imply genuine collaboration. Simply because something is 'research', or 'service design' does not automatically tell us what kind or level of engagement that implies.

Figure 3: Differentiating and mapping the full range of approaches to involving young people in health services research and service design
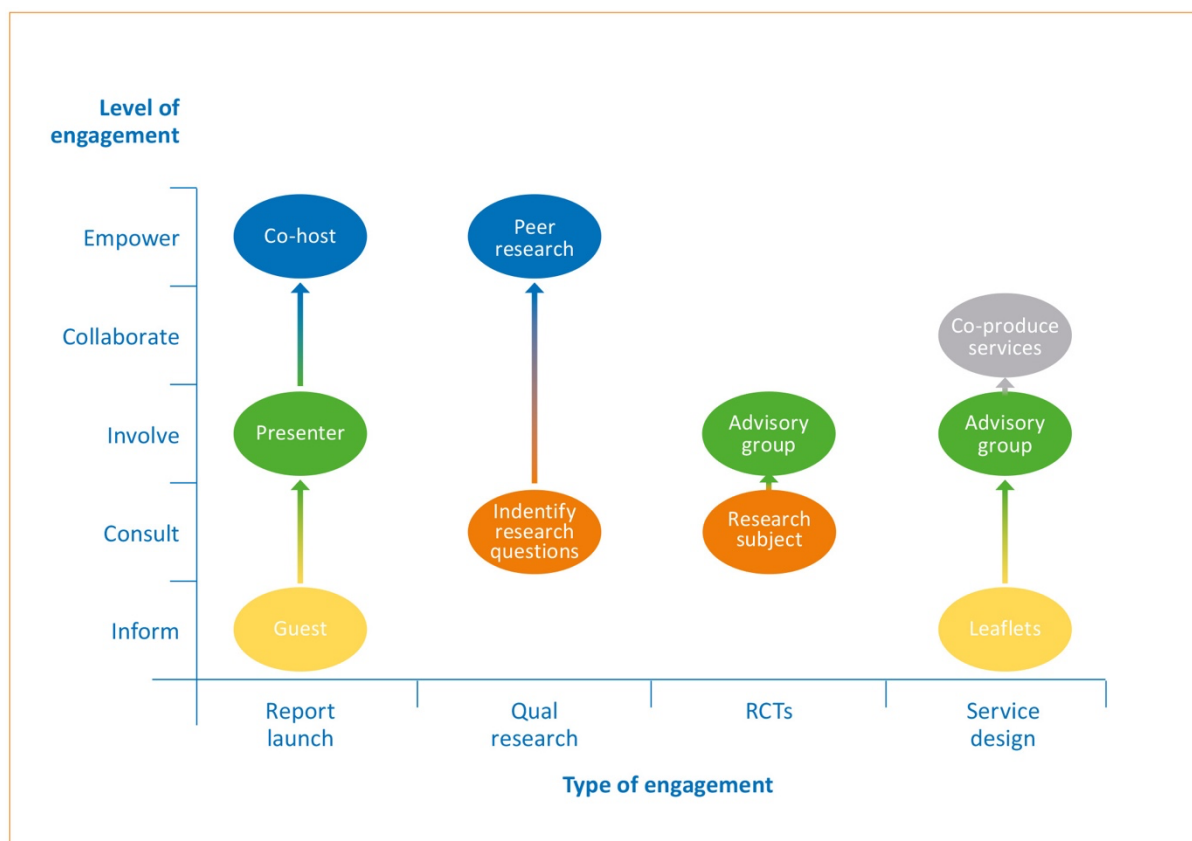
(2) Key constructs

How people have described these various activities differs in the literature. While there are different approaches and views of validity, the concept of 'research' is generally well understood (SciToons Brown University, 2020), but terms such as 'involvement', 'participation', 'engagement' or 'co-production' can be used in a number of different ways (Locock and Boaz, 2019). In some cases they seem to be used interchangeably, but in others they can mean quite distinct things.

Involvement, ***participation*** and ***engagement*** are the broadest terms. In the health service context these terms can mean both individual patient engagement or involvement in their own treatment, or more general involvement in research, service design and provision (Bombard et al, 2018). We are interested in the latter for the purposes of this paper. It seems there are few real distinctions between these three terms in how they are used; use appears to depend mainly on conventions of language within different domains and disciplines. All three carry connotations of doing things 'with' children and young people, rather than 'to' or 'about' them. As we have seen, engagement is often conceptualised as a spectrum.

Co-production has a much more specific meaning. Although it also shares the connotation of doing something 'with' young people, co-production implies a level of power sharing not present in other forms of engagement. At the simplest level, co-production involves deciding and acting together, in joint decision making and working groups. It often grows out of engagement and involvement activities that then develop into a higher level of participation. Locock and Boaz (2019) refer to co-production as an approach "...*where the lines between researcher and researched, between lay and expert, are deliberately blurred and challenged, underpinned by an egalitarian, emancipatory philosophy.*" Research and services can both be co-produced; where anything is produced, it can be 'co-produced'. Co-production has developed its own sets of methods such as the Experience-Based Co-Design Toolkit (Point of Care Foundation, 2021) or Nesta's six principles of co-production (Nesta, 2012).

Notions of **ethics** in relation to the whole spectrum of engagement are quite complicated. A common way of defining "ethics" is as norms for conduct that distinguish between acceptable and unacceptable behaviour (Resnick, 2020). Other definitions explain that ethics consist of rules, standards and principles, underpinned by morals and values (Open University, 2021). Beyond this, though, research ethics is a specialised discipline; a recent glossary of commonly used terms in research ethics defined nearly 200 items (Resnick, 2015). In a guide for A level students, the Wellcome Trust explains that: "*Research ethics are the moral principles that govern how researchers should carry out their work. These principles are used to shape research regulations agreed by groups such as university governing bodies, communities or governments. All researchers should follow any regulations that apply to their work.*" (Wellcome Trust, 2014).

Simply using co-production is considered ethical in some cases, so ethics becomes a general matter of principle (Tembo et al, 2021). At the other end of the spectrum is the work of formal university ethics committees, scrutinising the form of words used in consent forms, and applying very specific rules and standards. It has been stated that the primary purpose of ethics committees is threefold; to protect the rights of research participants, to ensure that research is worthwhile for society as a whole, and to treat researchers with respect and consideration (Gelling, 1999).

The discussions with young people undertaken as part of this project brought a different perspective, relating mostly to the protection of rights. Their interpretation of ethics related to what was 'fair', and the extent to which they were properly heard. However they also made reference to ethical issues around who was involved in research and participation, and issues of diversity and representation; the ethics around the extent to which the young people involved in projects can reflect the population they are intended to represent. This is a broader, 'meta' form of ethics not reflected in current formal definitions of ethics in relation to research and service development. The young people challenged the ethics of being asked to represent, for example, all young people from a particular ethnic group, or all young people with cancer, and the extent to which they felt this responsibility rested with them, rather than with the research or service design teams. We return to some of these important themes in sections below.

(3) Issues and contradictions

In the more traditional research literature, the main discussions around ethics in relation to young people generally focus on interrelated issues of consent, confidentiality and balancing protection and participation. In terms of informed consent, for example, there is a fair amount of comment and discussion around how to acquire it, what counts as informed consent at different ages, and how to secure ongoing consent (Morrow, 2009; Morrow and Richards, 1996). Many organisations such as the NHS Health Research Authority (2021) have set out the basic principles in relation to research, but there is a growing body of research on challenges of ensuring consent is fully informed for those under 18, and the importance of appropriate methods of communication (Vitiello, 2008; Grootens-Wiegers et al, 2015).

There are also critiques of existing research ethics procedures in the literature. In a study of the experiences of social science researchers in obtaining informed consent from children and young people, Sherwood and Parsons (2021) refer to the development of 'ethics in practice' by researchers who find they need to supplement official institutional ethics procedures with real world communication with children and young people experiencing marginalisation, finding the official procedures necessary but lacking. The aim is described as "authentic consent and appropriate participation". Others have also referred to "authentic involvement", which needs "space to talk" and "space to change" (Knowles et al, 2021). Something about institutional ethics procedures thus seems inauthentic. In Sherwood and Parson's (2021) study, social science researchers gained consent from young people through meeting institutional requirements, but then 'managed' the actual process more sensitively and respectfully, "*while also being mindful of the important administrative aspects of the process of seeking ethics approval*". The conclusion of this study was that there were ways of helping researchers manage the tensions (who can feel threatened or uncertain), rather than that there was anything fundamentally wrong with the institutional ethical approach.

Whittington (2019) goes further than this, concluding (from a discussion of ethics in navigating consent in the field of youth sexuality) that there is a need to develop robust participation and engagement strategies with an explicit focus on young people's competence, agency and rights to participate regardless of the perceived sensitivity of the topic. Young people say similar things (Munson and Frounks, 2015). It has been noted that there are limitations to the idea that young people are *"...'unfinished adults' who lack both rationality and moral agency, and who must be protected from the interests of academic institutions*." Pavarini et al, 2019). This may mean thinking differently about ethics. The message here is more that the basic underpinning of the consent procedures need to move beyond risk aversion to an approach more based on young people's rights to participation and protection (Skelton, 2008; Houghton, 2015; Liabo, Ingold and Roberts, 2017).

In a similar vein, Goredema-Braid (2010) introduced the interesting notion that there was a distinction between existing 'rules-based approaches' to ethical research with young people, versus a 'situated-based approach'. The latter emphasises the importance of making rational judgements rather than ruling in relation to ethical absolutes, introducing

more flexibility and a principle of 'care' rather than 'risk'. In addition there has been some commentary about the challenges of ethical approval in terms of the time and resources required, and the possibility that this might put some researchers off projects altogether, potentially limiting research progress (Audrey et al, 2016).

Issues around informed consent and other forms of ethics approval in <u>non</u>-research forms of engagement, co-production and co-design have received less attention in the literature, despite growing acknowledgement of the importance of involving young people in service development. Projects that are university based often simply report that the study was approved by an ethics committee. 'Grey' literature, practice reports and policy papers do not necessarily report any kind of ethics scrutiny, although institutions will usually have their own safeguarding policies that frame some aspects of the interaction. Safeguarding is not completely synonymous with ethics, though. It often depends on the context in which the activity is set. Co-production run by a university may require formal ethics, while the same activity undertaken by a different kind of organisation may not require any formal approval.

In addition, our own experience at AYPH has revealed that while formal 'research' parts of some collaborative research projects can go through ethics committees, some other aspects of engagement that are also part of the same project may not be part of that process, and consent to take part in different parts of the same project may vary.   Others note that there is little consensus on how to meaningfully engage patients and service users effectively and that methods and practices vary and are often based on local expertise and initiatives (Kaehne, Bray and Horowicz, 2020). Again, writers note tensions between protection and participation. As Liabo et al comment (2017), the risk reduction strategies that often underpin ethics approval processes can also carry risks - risks of non participation.

Existing commentary on young people's participation in research and co-production also occasionally raises the issue of 'gatekeeping'. Services and parents can either facilitate or limit their involvement. Some can be reluctant to pass information to young people as they are concerned about them being too vulnerable, or that they might not be 'academic' or reliable enough (Galliard et al, 2018). However, in other cases services and parents are crucial in both recruitment and ongoing engagement (Dewa et al 2020; Involve, 2019). In one study almost all young people who became engaged did so because healthcare professionals within the service understood the research and actively promoted the opportunity to young people and supported engagement (Brady et al 2018). As one author notes, "*the quality of the relationships between adults and young people and how they actively collaborate is the main component to youth participation.*" (O'Brien et al, 2018). Although we were focused on the health literature, this point also applies of course to education and other youth services research and activities.

(4) Identifying knowledge gaps and framing the questions

In addition to these issues, our scoping exercise and our engagement with young people have suggested other questions that are only very partially tackled in the existing literature, if at all. These include:

Are there underlying principles of ethics (including consent) that apply across different levels of engagement? The existing literature tends to be subdivided (research, versus service development), with little cross over. To what extent can all these different kinds of engagement be underpinned by shared principles, or to what extent do we need different frameworks for different kinds of engagement? Are there any ethical 'universals' for involving young people in our work, and if so, what are they? If we are to be serious about involving young people in all aspects of the research and service design processes, not just as research subjects, what other considerations need to be taken into account? Some of these questions have been raised in the existing literature (eg Locock and Boaz, 2019), but not systematically, and without clear answers.

Indeed, some of these questions are not easily answered. We are aware, for example, of differences and contradictions in how anonymity is treated in different activities, and any overarching framework would have to be able to tackle this. In some cases, young people may actively want to be recognised and acknowledged for their artistic and creative output that formed part of a research project, yet researchers may feel duty bound to protect anonymity because of ethics constraints. We know of other examples where involving young people as co-authors in outputs can also create the challenge of them potentially being identified when perhaps they had not been clear of the repercussions.

Are our current processes for ethical scrutiny appropriate and proportionate? A corollary of the previous question, this asks whether some parts of the continuum are over-scrutinised, and others under-scrutinised? How do we design ethical considerations proportionate and suitable for a range of different kinds of engagement – for example, the difference between being consulted at one stage, engaging in a sporadic or occasional way throughout a project, or being key team member such as a peer researcher? As far as we are aware, the issue of proportionality in ethical scrutiny across the engagement spectrum has not been addressed systematically to date. On the other hand, we have come across examples of how the ethics procedures can stifle youth participation in decision making; researchers may actively avoid public and patient involvement with young people because they feel ill equipped or under resourced to take on the ethics application and potential safeguarding considerations.

In terms of balancing protection and participation, how do we really empower young people and not just treat their engagement as tokenistic? This is certainly a topic of discussion in the sector of young people's health, and is a longstanding question (eg, Hart, 1992) but ethical considerations and challenges raised by this are still not properly unpacked in the literature. There are many high level statements that we need child centred ethics practices with the intention of empowering children and young people so that they can apply their agency (eg, Nuffield Council on Bioethics, 2015). There are also many commentaries referring to the issue of power dynamics between researchers and participants and between participants (eg, Farrimond, 2017; O'Brien et al, 2018). Power dynamics was an issue very clearly raised by the young people who contributed to this project.

However, as some writers note, "*Sharing control with the young people generated uncertainty, which meant that a supportive and respectful relationship between the lead researcher and the participatory artist was key*" (Involve, 2019). And as Liabo et al (2017) comment, there is a tension when the answers generated by co-production do not meet the original aims of the project; "*Aspirations for co-production fail if only those "answers" that are a good "fit" with researchers' or clinicians' paradigms are incorporated, and anything else explained or airbrushed away.*"

Is the way we think about ethics, protection and safeguarding fit for the more fluid kinds of engagement that are becoming more common? How do we deal with ethics as a process rather than an event? This issue is raised in several of the pieces we cite above, and again was clearly emphasised by the young people we spoke to. Where does the process start and end? As current procedures stand in research, ethical approval procedures can leave researchers considering approval as "ethics done" rather than "ethics started." (Liabo et al, 2017).   A result of this is that ethics can be seen as an obstacle to be overcome in complete research as opposed to a framework that needs to be revisited.   In principle, many would agree that consent - both for research and for service development - should be viewed as an ongoing process, not assuming that because someone said yes once they'll say it again (Liabo et al, 2017). This is partly because engagement is more meaningful if it is ongoing and shape-changing (Brady, 2020).

But in practice, how do we do this? The challenge of having the initial direction of a project altered by patient and public involvement (PPI) input was graphically illustrated in a recent article on 'authentic co-production' and we reproduce the diagram here (Knowles et al, 2021): Ethics needs to be able to flex appropriately in response to this kind of engagement.

Figure 4: How PPI changes a project
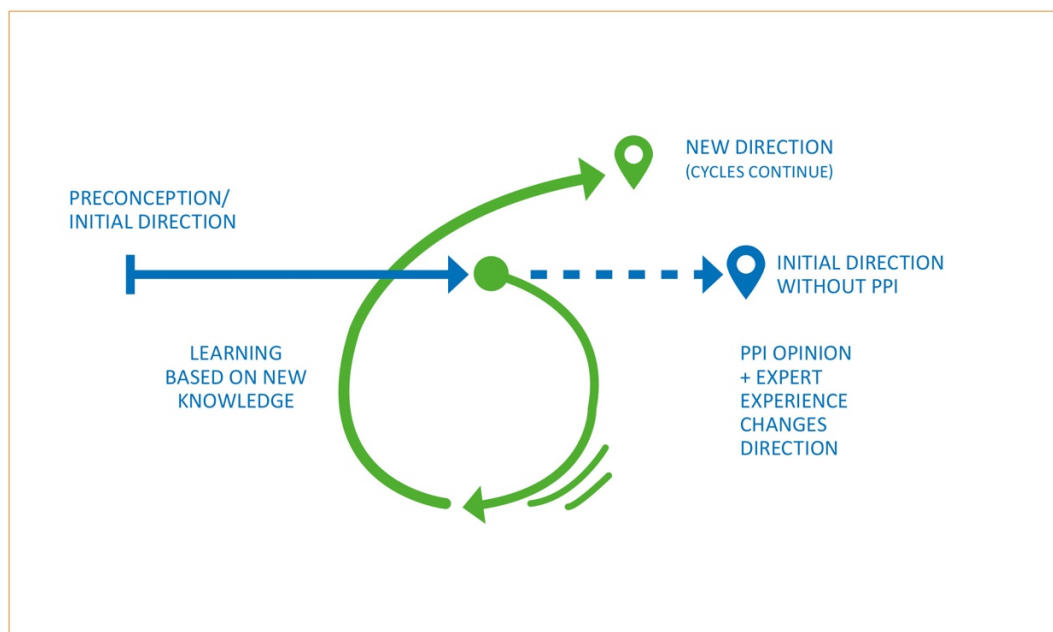
From Knowles et al (2021), reproduced with permission

Another element of flexibility relates to the need to take things into account such as the fact that some young people will be in temporary accommodation, or change mobile phones, have limited access to the internet etc - we need to work with young people to discuss the best way to keep in touch and ensure consent remains live (Brady et al, 2018).

How do we choose who is going to engage and how far can their views be representative; what is it that we actually want from engagement? The young people involved in the Common Room consultation exercise that was part of this project were very firmly of the opinion that this was an ethical issue, partly because it laid so much responsibility on them to be representative, and this could feel uncomfortable. Researchers have occasionally also raised the issue of ethics around representation (Liabo et al, 2017). The young people mentioned both the burden of being the representatives for sometimes very specific groups or even just general groups (feeling responsible for their peers and ensuring their opinion is heard). They also raised a lack of effort on the researcher/practitioner side in recruiting a diverse and representative group of young people - including issues of incentives and making assumptions that people can easily participate. Others have also noted the importance of diversity and representation with respect to the ethics committees and oversight bodies themselves. In a rare study asking their opinions of ethics committees, young people believed ethics committees should be diverse and include general members of the public, rather than reflecting a 'clique' of researchers and similar-minded people, suggesting committees should be constituted in a similar way to jury duty (Audrey et al, 2016).

To what extent do we need to be clear about the boundaries between different kinds of roles and relationships? This is not something that often arises in discussions around ethics, but it is something that we have seen arise as an issue in practice. For example, it is important that young people do not view the researcher as a 'friend' - the challenge is maintaining a balance, needing to minimise the distance between the adult and young person, but not leading to a misunderstanding of what the relationship is (Farrimond 2017). Others have also raised the issue of the boundaries between being a lay person and being considered a para-professional. This is not an issue in terms of traditional involvement in research projects, but becomes more of a challenge where the roles are flexible and evolving (Pavarini et al, 2019).

On the other hand, building and maintaining relationships in participation work is clearly a key part of the task. This encourages participants to speak, and creates a comfortable environment for them to do so; enabling young people to exercise their right to be heard was considered part of ethics by the young people in the Common Room consultation. In some cases, this relationship can continue past the end of the project. Indeed, if there is no participation worker or youth worker present there may be different demands placed on the researchers, who may not have been trained to respond; for example, to have expertise around participation safeguarding issues, and

potentially to be less boundaried in order to create the safest environment for a discussion to take place.

How best do we ensuring that consent is consent for all the aspects of engagement that will be experienced, and to ensure it is clearly understood? There is a considerable literature around ensuring informed consent by children involved in research, but less in relation to more fluid and dynamic forms of participation. How do we give young people good advice on what participation might actually mean and how to handle the consequences? There also is a danger in formal processes of getting caught up in semantics of consent as opposed to how it will translate to the individual and whether or not they will be able to understand what they're consenting to (Vitiello, 2008). There are related questions around the use of incentives (eg, Seymour, 2012).

How do we deal with ethics approvals in studies where the young people involved may include both children and adults? With the current NHS England emphasis on health services spanning 0-25, and a growing understanding of the challenges of the transition to adulthood when engaging with health services, it may be that we need more nuanced approaches that can managed the whole age period into early adulthood. To what extent are there ethics specific to children and how do these relate to, for example, 19 and 20 year olds? We have not seen this raised anywhere.

To what extent is youth engagement always appropriate? Quite rightly there has been a strong emphasis on the value of bringing youth voice into as many aspects of our research and service development work as possible. However, there are perhaps some unasked questions about whether it is always appropriate to involve young people in all the pieces of work we do. Involving young people has certainly become popular and there is a danger that it becomes another 'tick box' activity. However, some of what we ask them to do may be much less appropriate or interesting for young people. Have we established a general rule if the piece of work is going to have a direct or indirect impact on young people then young people should in some way be involved? The answer may well be yes, but we have not seen the question discussed.

Do we know enough about what young people think? In relation, for example, to the previous question. The answer here is undoubtedly 'no'. We have cited a small number of papers that have included young people's perspectives on ethics, but these are in the minority. The young people we spoke to reflected a rather different view from the majority of the papers we have reviewed, in the sense that their starting point was what was 'fair', and the extent to which they were properly heard, not how to manage risk.

Our overall sense is that existing systems do not tackle the complexity of involving young people in more ongoing and dynamic forms of engagement, although some of the resource packs on engagement have much more coverage of this than research ethics frameworks.

(5) Existing ethical guidance and frameworks

As part of the project we took a look at existing ethical guidance and frameworks. Clearly this is a substantial task, so we have only highlighted a few that exemplify the resources currently available. In general they fall into the two camps identified throughout this report, with little overlap; either frameworks for research ethics, or frameworks for patient and public involvement. In both cases they may or may not be specific to our age group of young people age 10-24, but we have focused on those that relate to children and young people. There are other, broader research ethics frameworks that cover all human subjects.

Examples for children and young people in relation to research include:

(1) [NIHR guidance on involving children and young people in research](#). In 2021 NIHR updated and republished their 2016 advice, containing 13 top tips identified by young people themselves (NIHR, 2021b).

(2) [Royal College of Paediatrics and Child (RCPCH) Health Research Charter](#) for Infants, Children and Young People's Child Health. The RCPCH Charter aims to support children, young people, families and health professionals to talk about child health research and guide discussions to ensure everyone is clear on what is happening, when and why child health research is important.

(3) [Economic and Social Research Council Research with Children and Young People](#). A brief introduction that covers particular considerations around children's vulnerabilities and capacities, issues around consent, and links to other resources.

(4) [NSPCC Research with children: Ethics, safety and avoiding harm](#). Information for researchers on how to manage the risk of harm to participants, how to obtain informed consent, and what to do with concerns of abuse.

(5) Guidance on the involvement of children and young people in clinical trials (eg, Modi et al 2014).

Examples in relation to involving children in health service development are fewer and tend to be about 'how to engage' rather than on the ethical considerations. Often engagement guides are focused on involving children and young people in their own care, rather than in service development. Some examples of service development examples include:

(1) [North West Leicester Effective Involvement of Children and Young People](#) resource pack. A good example of a thorough introduction to the issues and checklists to guide practitioners (but note, not specific to health)

(2) Guides on involving children and young people in social care (again, not specific to health), including the Social Care Institute of Excellence https://www.scie.org.uk/publications/guides/guide11/

(3) Brady's framework for embedding young people's participation in health services (Brady, 2020).

Overall, although many guidelines do exist, very few have been developed with young people, and generally they do not consider the full range of activities from engagement to academic research.

Conclusion

Young people's role in both research and service design has modernised in recent years. Expectations around user engagement have substantially evolved. Participation, co-production and design - these are all critical to enriching our research and service design projects, and there is clear evidence that 'authentic' engagement of young people produces better research and services, and potentially improves young people's experiences and even health outcomes. It is critical that we move beyond viewing the associated ethics approval process as something that researchers have to 'get through' before they can start. It is also critical that the appropriate levels of ethical scrutiny are applied to all sorts of engagement with young people, not just that falling into traditional forms of academic research.

The existing literature on this topic is piecemeal. People comment on their area of interest but there is much less across the whole piece. Research has looked at research ethics, and co-production at co-production techniques. Generally the systems for approval are separate and different, and often less formal in the latter. The ethics of co-production with young people for the purposes of service design gets much less attention overall.

Furthermore, we have found very little in the research literature that looks at ethics from young people's perspectives. In fact only one paper was located that really takes this perspective, and that was about young people's views about the purpose and composition of research ethics committees.

Our conclusion is that there are a number of questions that need answering, and the existing frameworks need revising in the light of the more participatory and engaged way we involve young people in lots of different aspects of our work. We need to determine whether we can share an ethical framework that works across the whole of the engagement spectrum, or whether we need different versions for different tasks. Whatever the outcome, it seems there is a need to modernise the work of research ethics committees to reflect the reality of how we work with young people in the real world. We are committed to ethical governance frameworks that shape our approach, but we do not think the right ones currently exist for the kind of work being undertaken with young people to inform research, policy and practice.

References

Arnstein S (1969) A ladder of citizen participation, *Journal of American Planning Association*, Vol. 35, No 4, July, pp. 216 - 224.

Association for Young People's Health (2018) Aspirations, opportunities and challenges: Youth led research report into the lives of young people in Kensington and Chelsea. London: AYPH

Association for Young People' Health and the Together Project Team (2020) *Setting up group clinics for young adults living with diabetes: Initial findings from a feasibility study* London: AYPH

Audrey, S., Brown, L., Campbell, R. Boyd A and Macleod J (2016) Young people's views about the purpose and composition of research ethics committees: findings from the PEARL qualitative study. *BMC Medical Ethics* **17,** 53

Bombard Y, Baker GR, Orlando E *et al*.(2018) Engaging patients to improve quality of care: a systematic review. *Implementation Sci* **13,** 98

Bovairt T (2007) Beyond Engagement and Participation: User and Community Coproduction of Public Services *Public Administration Review* Sept, 846-860

BMJ (2019) *Rapid Response: Is PPI being privatised?* Accessed 18 October 2021

Braam K, van Dijk-Lokkaret Em Kaspers G et al (2018) Effects of a combined physical and psychosocial training for children with cancer: a randomized controlled trial *BMC Cancer* 18, Article number: 1289

Brady L-M, Templeton L, Toner P, Watson J, Evans D, Percy-Smith B and Copello A (2018), "Involving young people in drug and alcohol research", *Drugs and Alcohol Today* 18(1) 28-38.

Brady, L (2020) (Ed) *Embedding Young People's Participation in Health Services*: New Approaches. Bristol: Policy Press

British Youth Council (2021) NHS Youth Forum. Accessed 18 October 2021.

Brooks F, Klemera E, Chester K, Magnusson J & Spencer N (2020). *HBSC England National Report: Findings from the 2018 HBSC study for England*. Hatfield, England: University of Hertfordshire

DECIPHer (2021) *Public Involvement/ALPHA*. Accessed 18 October 2021

Dewa L, Lawrence-Jones A, Crandell C, Jaques J, Pickles K, Lavell M, Pappa S and Aylin P (2020) Reflections, impact and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties. *Health Expect.* 24 Suppl 1, 134-146

ESRC (2015) *ESRC Framework for research ethics*. Accessed 18 October 2021.

Evans D, Coad J, Cottrell K, et al (2014) *Public involvement in research: assessing impact through a realist evaluation.* Southampton (UK): NIHR Journals Library (Health Services and Delivery Research, No. 2.36.) Accessed 18 October 2021

Farrimond, H. (2017) The ethics of research, Chapter 3, in The BERA/SAGE Handbook of Educational Research, Eds: Dominic Wyse, Emma Smith, Larry E. Suter and Neil Selwyn, London, New York: SAGE Publications Ltd.

Funder's Collaborative on Youth Organising (2003) *An Emerging Model for Working with Youth: Community Organizing + Youth Development = Youth Organizing* New York

Gaillard S, Malik S, Preston J, Escalera BN, Dicks P, Touil N, Mardirossian S, Claverol-Torres J, Kassaï B (2018) Involving children and young people in clinical research through the

forum of a European Young Persons' Advisory Group: needs and challenges. *Fundam Clin Pharmacol*. 32(4):357-362.

Gelling L (1999) The role of the research ethics committee. *Nurse Education Today* 19, 564–569

Goredema-Braid B (2010) Ethical research with young people. *Research Ethics Review* v(2) 48-52

Greater Manchester Combined Authority (2020) *December 2020 blog from Chair of Youth Task Force* Accessed 18 October 2021

Grootens-Wiegers P, de Vries M, van Beusekom M, van Dijck L, van den Broek J (2015) Comic strips help children understand medical research: Targeting the informed consent procedure to children's needs, *Patient Education and Counseling*, Volume 98, Issue 4, 518-524,

Hagell A, Rigby E and the peer-led research team (2018) Aspirations, opportunities and challenges Youth led research into the lives of young people in Kensington and Chelsea . London: AYPH Accessed 12 February 2022

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

Houghton C (2015) Young people's perspectives on participatory ethics: Agency, power and impact in domestic abuse research and policy-making. *Child Abuse Review* 24(4) 235-248

IAP2 (2014) *IAP2's public participation spectrum*. Accessed 18 October 2021

Imperial College London (2020) *Medical student wins prestigious Diana award.* Accessed 18 October 2021

INVOLVE (2019) *Co-production in Action: Number One.* Southampton, INVOLVE (McAnuff and Barker) Accessed 12 February 2022

James M, Christian D, Scott S, *et al* (2019) What works best when implementing a physical activity intervention for teenagers? Reflections from the ACTIVE Project: a qualitative study *BMJ Open*;**9:**e025618. doi: 10.1136/bmjopen-2018-025

Kaehne A, Bray L and Horowicz E. (2020) Co-producing health care - pragmatic principles and an illustration *Emerald Open Res* **2**:10 ()

Knowles, S.E., Allen, D., Donnelly, A. *et al* (2021) More than a method: trusting relationships, productive tensions, and two-way learning as mechanisms of authentic co-production. *Res Involv Engagem* **7,** 34.

Lancet Child and Adolescent Health (2021) Editorial Expanding our youth engagement—join us! Vol 5, 233 Accessed 18 October 2021

Liabo K, Ingold A and Roberts H (2017) Co-production with "vulnerable" groups: Balancing protection and participation *Health Science Reports*, 1(3) e19

Locock L and Boaz A (2019) Drawing straight lines along blurred boundaries: qualitative research, patient and public involvement in medical research, co-production and co-design. *Evidence & Policy: A Journal of Research, Debate and Practice*. 15(3) 409-421

Matthew, L., Barron, I. & Hodson, A. (2019) Participatory Action Research: Confidentiality and Attitudes of Victimized Young People Unknown to Child Protection Agencies. *Int. Journal on Child Malt.* **2,** 79–97

Modi N, Vohra J, Preston J for a Working Party of the Royal College of Paediatrics and Child Health*, et al* (2014) Guidance on clinical research involving infants, children and young people: an update for researchers and research ethics committees. *Archives of Disease in Childhood* ;**99:**887-891.

Morrow V (2009) Ethical dilemmas in research with children and young people about their social environments *Children's Geographies*, 6(1) 49-61

Morrow V and Richards M (1996) The ethics of social research with children: an overview. *Children and Society* 10, 90-105

Munson R and Frounks A (2015*) Blog: Young people want control over consent, confidentiality and comment.* Accessed 11 February 2022

Nesta (2012) *People Powered Health Co-production Catalogue*. Accessed 18 October 2021 https://media.nesta.org.uk/documents/co-production_catalogue.pdf

NHS England (2021) *Children and young people.* Accessed 18 October 2021.

NHS Health Research Authority (2021) 'Principles of consent: Children and Young People. Accessed 18 October 2021

NIHR (2021a) *Briefing notes for researchers – public involvement in NHS, health and social care research* Accessed 12 February 2022

NIHR (2021b) *Involving children and young people as advisors in research; top tips and essential key issues for researchers*. Accessed 12 February 2022

Nuffield Council on Bioethics (2016) *Statement of aspiration: Improving research by involving children and young people.* London: Nuffield Council on Bioethics. Accessed 12 February 2022

O'Brien N, Munn-Giddings C, Moules T (2018) *The Ethics of Involving Young People Directly in the Research Process.* Childhood Remixed, May (2018). pp. 115-128. ISSN 2515-4516

Open University (2021) *OpenLearn: A question of ethics: right or wrong?* Accessed 18 October 2021 https://www.open.edu/openlearn/health-sports-psychology/question-ethics-right-or-wrong/content-section-1

(Parsons S, Sherwood G and Abbot C (2015) Informed Consent with Children and Young People in Social Research: Is There Scope for Innovation? *Children and Society*, 20(2) 132-145)

Pavarini G, Lorimer J, Manzini A, Goundrey-Smith E, Sing I (2019) Co-producing research with youth: The NeurOx young people's advisory group model. *Health Expect.* 22(4): 743–751.

Point of Care Foundation (2021) *Experience-based co-production toolkit*. Accessed 18 October 2021 https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/

Resnick D (2015) *Glossary of Commonly Used Terms in Research Ethics*. National Institute of Environmental Health Sciences. Accessed 18 October 2021 https://www.niehs.nih.gov/research/resources/bioethics/glossary/index.cfm

Resnick D (2020) *What Is Ethics in Research & Why Is It Important?* National Institute of Environmental Health Sciences. Accessed 18 October 2021 https://www.niehs.nih.gov/research/resources/bioethics/whatis/index.cfm

Royal Society for Public Health (2021) *What is the Young Health Champions Programme?* Accessed 18 October 2021 https://www.rsph.org.uk/our-work/programmes-hub/young-health-champions.html

SCIE (2021) Co-production in social care: What it is and how to do it: What is co-production - Defining co-production. Accessed 18 October 2021 https://www.scie.org.uk/publications/guides/guide51/what-is-coproduction/defining-coproduction.asp

SciToons Brown University (2020) *Video: What is Research?* Accessed 12 February 2022

Seymour, K. (2012). Using incentives: encouraging and recognising participation in youth research, *Youth Studies Australia*, 31 (3), 51-59.

Sherwood G and Parsons S 92021) Negotiating the practicalities of informed consent in the field with children and young people: learning from social science researchers. *Research Ethics,* 17(4), 448-463

Skelton T (2008) Research with children and young people: exploring the tensions between ethics, competence and participation. *Children's Geographies*, 6(1) 21-36

Tembo D, Hickey G, Montenegro C, Chandler D, Nelson E, Porter K et al (2021) Effective engagement and involvement with community stakeholders in the co-production of global health research *BMJ* 372:n178

Transition to Adulthood (2021) *Case Studies*. Accessed 18 October 2021

UN General Assembly (1989) *Convention on the Rights of the Child,* 20 November 1989, United Nations, Treaty Series, vol. 1577, accessed 18 October 2021

University of Nevada (2021) History of Research Ethics. Accessed 18 October 2021

Vitiello B (2008) Effectively Obtaining Informed Consent for Child and Adolescent Participation in Mental Health Research, *Ethics & Behavior*, 18:2-3, 182-198

Wellcome Trust (2014) *Ensuring your research is ethical: A guide for Extended Project Qualification students* London: Welcome Trust. Accessed 18 October 2021

Whittington E (2019), Co-producing and navigating consent in participatory research with young people, Journal of Children's Services 14 (3), pp. 205-216.

Wong NT, Zimmerman MA and Parker EA (2010), A Typology of Youth Participation and Empowerment for Child and Adolescent Health Promotion. American Journal of Community Psychology, 46: 100-114

Young Trustees Movement (2021) Website. Accessed 18 October 2021

More information

This scoping review was prepared by the Association for Young People's Health (AYPH). AYPH is the UK's leading independent voice for youth health. We work to improve the health and wellbeing of 10-24 year olds. We do this by involving young people in our work and making sure their views are heard, working with healthcare providers to improve services for young people, improving access to information, resources and innovation, promoting evidence-based practice and highlighting important data, and increasing communication between practitioners from different sectors.

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