RHETORIC TO REALITY: AN INQUIRY INTO EMBEDDING YOUNG PEOPLE'S PARTICIPATION IN HEALTH SERVICES AND RESEARCH

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Abstract

Whilst there is growing awareness of the case for children and young people's participation across the public sector, there is limited evidence on how this apparent commitment to participation and children's rights translates into professional practice and young people's experience of participation in health services and research. Participation in health tends to be driven by a public involvement and engagement agenda rather than discourses of participatory practice. Young people's views are still not consistently sought or acknowledged within healthcare settings; they are rarely involved in decision-making processes and often occupy a marginalized position in healthcare encounters. In addition to the piecemeal approach to participation in health services there have also been disparities in the characteristics of young people likely to participate, the types of decisions they are involved in making, and the extent to which this participation is meaningful and effective.

This study drew on theories of participation and childhood, and considered how these were informed by debates around children's rights, citizenship and agency in relation to young people's participation in health services and research. Using a participative research approach informed by an action research methodology, the study sought to explore how participation was understood and operationalised in two case studies: a community children's health partnership and a randomised controlled feasibility trial. Through working collaboratively with adults and young people in these case studies, and informed by a wider process of collaborative inquiry, the study sought to build capacity through learning to inform the embedding of participation.

This study found that participation in health services and research was still conceptualised primarily as adult-initiated, context-specific collective participation in formal settings which potentially excludes some of the young people most likely to use health services and limits the potential for fundamental change. The learning from the study identified the potential for new approaches which would do more to transfer power to young people, and informed a rights-based framework for embedding participation in practice.

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Glossary

CAMHS: Child and Adolescent Mental Health Services

CCHP: Community Children's Health Partnership (case study one)

CRC: United Nations Convention on the Rights of the Child (UN, 1989)

CYP: Children and young people

HTA: NIHR Health Technology Assessment programme (funder of Y-SBNT study)

HYPE: Helping Young People (and children and families) to Engage (Barnardo's service and one of the partners in CCHP)

INVOLVE: NIHR national advisory body for public involvement in NHS, public health and social care research

NIHR: National Institute for Health Research

NHS: National Health Service

PPI: Patient and public involvement (also 'public involvement')

TMG: Y-SBNT trial management group (the research team)

TSC: Y-SBNT trial steering committee

UK: United Kingdom of Great Britain and Northern Ireland

UWE: University of the West of England

YP: Young people

YPAG: Young people's advisory group

Y-SBNT: Youth Social Behaviour and Network Therapy study (case study two)

1. Introduction

1.1 The context for this study

The case for children and young people's participation has been well-documented (e.g. Kirby *et al.*, 2003; Percy-Smith and Thomas, 2010), and it is a popular concept in many healthcare organisations (Percy-Smith, 2007; Weil *et al.*, 2015) and in health research. The United Nations Convention on the Rights of the Child (CRC) (UN, 1989) has established international recognition that all children have a right to the highest possible standards of both healthcare and participation (Alderson, 2014). But participation is a multi-layered (Kirby *et al.*, 2003; Sinclair, 2004) and sometimes contested concept (Lansdown, 2006; Shaw, Brady and Davey, 2011). Participation can broadly be framed as being at the level of individual decision-making (children and young people's participation in decisions that affect their own lives) or at a more strategic level (participation in policy and service development and other areas that affect children and young people collectively) (Kirby *et al.*, 2003; Wright *et al.*, 2006). This study is concerned with both individual and strategic participation, and the links between them, as well as the ways in which health services and research provide opportunities for children and young people to participate within the context of their systems and practice. Many popular models and approaches appear to suggest a depoliticisation of children and young people's rights and participation (Nolas, 2015) with the dominant structures for strategic participation, such as youth forums, councils and advisory groups, favouring adult-led and context-specific participation rather than challenging adult-child power relations (Davis and Hill, 2006). This raises concerns, which this study sought to address, about whether and when participation is meaningful for all those involved, effective in terms of impacts on service decision-making and outcomes for children and young people, and sustained (Crowley, 2015; Percy-Smith, 2010).

Any consideration of children and young people's participation in institutional contexts requires an understanding of *"the dynamics of power and control which operate in their relations with adults"* (Devine, 2002, p.303). This study therefore sought to address the need for greater understanding of how institutional and socio-cultural contexts inform the application of different typologies of participation identified by Tisdall *et al.* (2014). This study was undertaken at a time when children and young people's participation in health services and research had an increasingly high profile. The CRC-informed understanding that children and young people should be involved in decisions which affect them is increasingly reflected in law, guidance, regulation and policy in relation to health and more widely (Franklin and Sloper, 2005). There have been repeated calls to involve patients and members of the public in healthcare improvement in response to serious

clinical and service failings in the United Kingdom (UK) and internationally (Ocloo and Matthews, 2016). But the extent to which there is a genuine commitment to children's rights and participation in the health sector in practice is something this study sought to question. Furthermore there is limited evidence on how stated commitments translate into changes in systems, practices and children and young people's experience of participation and of services; and on the authenticity of that participation.

This study took place during a period of political and economic flux in the UK and in particular on-going and substantive changes to health services and research. Austerity measures have reduced the range of health services which protect and fulfil children and young people's rights (Children's Commissioners, 2015) and mean that many children and young people are not receiving appropriate healthcare when they need it (CRAE, 2015a). There are widespread assumptions about children and young people's competence, especially in relation to healthcare decision-making (Coyne and Harder, 2011). The way in which children, childhood and youth are conceptualised raise issues of power and tensions between participation, protection and provision rights in healthcare (Alderson, 2014; Franklin and Sloper, 2005; Jones and Welch, 2010). These assumptions are often linked to Gillick competency and the associated Fraser Guidelines (Gillick v West Norfolk, 1984), widely used in healthcare to assess whether children and young people have the maturity to make their own decisions and to understand the implications of those decisions (NSPCC, 2016). The tensions between perceptions of children and young people as competent or incompetent underlie many of the ambiguities of children and young people's participation (Cockburn, 2005). The dominant model in healthcare is still one in which children and young people are rarely involved in making decisions about matters which affect them, in spite of the drive for children and young people's participation and public involvement and engagement more generally. However even if children and young people are deemed competent this does not address the fact that health professionals and parents have significant influence on the decision-making capacity of children and young people and on the participation process (Schalkers *et al.*, 2016).

Alongside increasing recognition of the importance of children and young people's participation in health services, there is growing interest in research which evaluates the healthcare experiences of children and young people (Clavering and McLaughlin, 2010). A focus on children's rights and changing views of the nature of childhood has, to some extent, been reflected in increasing interest in children and young people's participation in research (e.g. Kellet, 2005; Kirby, 2004; Powell and Smith, 2009; Shaw, Brady and Davey, 2011) both as sources of data and through their active participation in the planning and process of research. Public involvement is now an essential element of all publicly-funded

health research in the UK (Evans *et al.*, 2014), although this involvement is variable and often lacks a clear ideological basis (Beresford, 2013). The increasing overlap between participation in health services and health research is an under-researched area which this study sought to address. Research that actively involves children and young people should lead to research, and ultimately services, that better reflect their priorities and concerns (Brady *et al*, 2012; Fleming and Boeck, 2012) and enhance the opportunity for optimal health outcomes (Jamal *et al.*, 2014). However there is a lack of evidence on the impact of children and young people's participation in health research (Bird, Culley and Lakhanpaul, 2013; Wilson *et al.* 2015). As with health services there is a gap between the rhetoric of participation and the reality of practice, particularly when children and young people are deemed to be more 'vulnerable' (Berrick, Frasch, and Fox, 2000).

1.2 A note on terminology

Defining 'childhood' and 'youth'

'Childhood' has many and varied definitions including *"the status of being a minor, the early-life state of immaturity whether actual or ascribed and the process of growing towards adulthood"* (Alderson, 2013, p.4). 'Children' are generally understood to be those below the age of 18 (McNeish, 1999), however although 'youth' or 'young people' is commonly defined as 15-25 years old it can sometimes include those aged up to 35 (UNESCO, 2016). So although there is overlap between 'children' and 'young people' the terms are not synonymous. Young people were the main focus of this study, and this is therefore the term generally used in this thesis. Although the young collaborators in my case studies were involved because of their experience of using health services when under the age of 18, their ages at the time of the study ranged from 13 to 21. However many of the debates and issues in the literature, and the implications of this study, are equally relevant to children's participation so where appropriate I refer to 'children and young people'. Furthermore I also talk about 'children's rights' as the CRC is a convention on 'the rights of the child' although this does include young people under the age of 18.

Defining 'participation'

'Participation', 'shared decision-making', 'partnership' and 'inclusion' are often used interchangeably when discussing the involvement of children and young people in health services (McPherson, 2010). Different terminology, theories and approaches to describe patient and public participation in health services:

> *"...have emerged from disparate social movements, policies and practices...[including] consultation, engagement, participation, partnership or co-production. These have sometimes been used to imply a greater or lesser level of involvement, power and influence in decision-making processes within an organisation. However this language does not always reflect the underlying ethos of these involvement activities."* (Ocloo and Matthews, 2016, p.2)

Some of these terms imply a greater level of influence or power but one cannot assume that terminology necessarily reflects the underlying ethos or purpose (Faulkner *et al.*, 2015), or indeed common understandings of these terms. To complicate things further there is a cultural difference between the field of children and young people's participation and health research, where the term of choice is 'public involvement' and participation and engagement have very different and specific meanings. In health research involvement is commonly defined as "*research...carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"*, whereas 'participation' refers to *"where people take part in a research study"* (i.e. as sources of data) (INVOLVE, 2016a). This complexity of terminology may reflect conceptual differences or confusion, discussed further in 2.2.1. In the absence of consensus on terminology I have used 'participation' wherever possible in this thesis to describe processes by which individual children and young people influence decisions which bring about change in themselves, their peers, the services they use and their communities (Kirby *et al.*, 2003; Tresder, 1997; Participation Works, 2010). I have tried to be as clear and consistent as possible in my use of the terminology of participation in this thesis. However the absence of consensus within and between health services and research means that this has not always been possible: for example in quotations which refer to PPI (patient and public involvement) in health research. I found that questions of terminology and underlying ethos were central to understanding how the rhetoric around children and young people's participation rights becomes embedded in practice, and this thesis therefore considers how these terms were used, by whom, and the values and meanings ascribed to them.

1.3 My background

I have longstanding interests in participation in health and social care services, disability and children's rights and inclusive and participatory research methods. I started my career in social care, working as a support worker in mental health and learning disability services, before undertaking research for the organisation for which I worked (on the changing housing needs of their ageing population of learning disabled service users). My MSc research, undertaken in collaboration with the Royal National Institute for Deaf People (now Action on Hearing Loss) used participatory methods to explore how deaf and deafblind users of residential care services could inform service development (Brady, 2002). I subsequently worked mainly in rights-based organisations including the Disability

Rights Commission and the National Children's Bureau (NCB) Research Centre. Thus my research career to date has focused on social research which has practical application for policy and practice. I have continued to be interested in research as a tool for social change both by undertaking research which aims to change policy and practice, and through using participatory approaches to support the public involvement in research (e.g. Brady *et al.* 2011 and 2012). I also led the NCB's Research Centre's work on the participation of children and young people in research for the four years prior to starting this PhD, with a particular focus on involvement in health and social care research.

During my doctoral studies I continued to be engaged in research and practice around children and young people's participation in health services and research, not least as a participation lead for the Youth Social Behaviour and Network Therapy (Y-SBNT) pilot clinical trial which was one of the case studies for my doctoral research. As a member of the National Institute for Health Research (NIHR) INVOLVE advisory group I was a member of steering groups for the development of guidance on social media for public involvement and the involvement of children and young people in health and social care research, both of which had relevance to this study. I developed and facilitated workshops on children and young people's involvement in health research for the NIHR Biomedical Research Centre at Guy's and St Thomas NHS Foundation Trust and King's College London, as well as contributing to workshops on a similar theme with People in Research West of England. I was also a consultant to Ipsos MORI on a project for Great Ormond Street Hospital to develop patient-reported experience measures, including contributing to the development of data collection tools and co-facilitating focus groups with young people using the hospital. In summer 2016, prior to submitting this thesis, I co-facilitated a workshop for Wellchild on embedding the participation of children and young people in the organisation's work. I also facilitated a 'young people's strategy day' for the Albert Kennedy Trust to support young people's input into the organisation's work with lesbian, gay, bisexual, transgender and transsexual young people facing homelessness.

My aim here is not to list my curriculum vitae but rather to illustrate how my background, and continuing work, in children and young people's participation in health services and research informed both my interest in this PhD and how I approached the research topic. I did not come to this PhD in the traditional way, as a *"bright young thing"* seeking *"an apprenticeship for academic research"* (Nature, 2011, p.260). Rather the PhD scholarship provided me with an opportunity to develop a more in-depth and rigorous understanding of an area in which I had long been interested, to develop my own theoretical understanding and research skills and to make a contribution to policy and practice. Throughout the research process I critically reflected on the understandings, values,

preconceptions and actions that I brought to this study, and how I located myself in facilitating co-learning, participation and organisational transformation.

1.4 Initial questions

This study is concerned with the translation of the rhetoric of young people's participation into the reality of practice; how cultures, systems and processes support or create barriers to the embedding of participation. From the outset I was particularly interested in the extent to which understandings of young people's rights, citizenship and power informed participatory practice in healthcare and health research environments. Related to this were the issues of how, when and by whom opportunities for participation were created and what was needed for these to become embedded. One of the aims of the study was to provide insight into the complexities at play in realising existing theories and models of participation in practice. I wanted to develop understanding which could support the embedding of young people's participation in health services and research, drawing on theory and practice in relation to participation and rights, public involvement in research and participatory research approaches. Furthermore, in a sector in which there are still widespread assumptions about young people's competence and vulnerability, I wanted to better understanding of the tensions between participation, protection and provision rights in health and the implications for participation.

This study set out to investigate the ways in which young people's participation can be embedded in health services and health research. In action research, research questions emerge from engagement with participants, but the concerns which motivated me at the outset were to understand how people conceptualised young people's participation, the reality of how these understandings of participation were operationalised and the barriers and challenges faced when attempting to embed participation in practice.

As the starting point for participatory inquiry these concerns *"cut across and introduce[d] the possibilities for change on multiple levels"* (Herr and Anderson, 2015, p.91). They represented a starting point for my work with the two case studies, with the research process then helping to refine both questions and methods (Dick, 2002).

2. Theoretical approaches to children and young people's participation

This chapter locates the study within the wider literature concerning participation and childhood, and considers how these are informed by debates around children's rights, citizenship and agency in relation to their participation in health services and research. It ends by setting out the theoretical framework for this study. Chapter 3 then considers the evidence for the application of this theoretical framework in legislation, policy, and the practice of children and young people's participation in UK health services and research.

2.1 Approach to the literature

In order to develop a theoretically-informed rationale for this study (Braun and Clarke, 2013) this thesis draws on a critical review of the academic literature and other sources of information and evidence relevant to children and young people's participation in health services and research. Although it was not a systematic review the process nonetheless followed a rigorous protocol, outlined in Appendix 1.

Rather than starting from too fixed a theoretical position I wanted to allow:

> *"…for openness and flexibility as the study develops [while having]… a good sense of the substantive issues that the research topic involves, and to be clear about how they build on, and might add to, what has been generated by previous research."* (Ritchie, *et al.*, 2014, p.52)

My reading of the literature was therefore an interactive, iterative process. One of the challenges is that there is not a clearly defined body of literature related to my research questions. Source material was multi-disciplinary and incorporated literature from both peer-reviewed and 'grey' literature. I therefore drew particularly on the literature on children's rights, participation, childhood studies, health studies, and public involvement in both service delivery and research as these were most directly relevant to my research topic. The literature on disability studies, youth work and social policy more broadly also have relevance to this research, and I have drawn accordingly on some of the key literature in these fields. But, given the sheer volume of potentially relevant material, this review was not intended to be comprehensive but rather to enable me to identify the literature most relevant to my research questions.

2.2 Understandings of participation

2.2.1 Defining 'participation'

A recent evaluation of children and young people's participation across the European Union (ECORYS, 2015) highlighted the extent to which understandings of participation are

central to the way it manifests in practice. Before considering how participation may be embedded it needs to be defined, but the terminology of participation can be opaque *"with the same word being used to describe very varied activity in very differing circumstances"* (Kirby *et al.*, 2003, p.21). It can mean taking part in an activity or in decision-making, and a process or an outcome (Thomas, 2007). The starting point for this study was the commonly-held understanding of participation as a process by which children and young people influence decisions which bring about change in themselves, their peers, the services they use and their communities (e.g. Tresder, 1997; Participation Works, 2010). However Boyden and Ennew (1997), Percy-Smith (2016) and others have argued that such an understanding of participation implies only taking part or being present, children and young people 'having their voices heard' or 'sharing their views' rather than working in collaborative relationships with adults. Talking about children and young people 'influencing decisions' does not necessarily denote a transfer of power (Boyden and Ennew, 1997), and indeed may imply that the scope for children and young people's influence is determined and controlled by adults. The ways in which conceptualisations of participation inform practice, and children and young people's experiences, were therefore key issues for this study in seeking to understand how participation can be embedded.

Distinctions are often drawn between participation and consultation as well as between different levels of participation (Thomas, 2007; Kirby *et al.*, 2003). Levels of participation are discussed in 2.2 below in relation typologies of participation, but the question of consultation has particular relevance to how participation is defined. In some instances consultation is defined as a sub-category of participation, but in others it is seen as different to active participation (Sinclair, 2004; Thomas, 2007). Consultation is described as 'seeking views' and 'being listened to' as opposed to genuinely participatory practice in which children and young people are directly involved in decision-making (Hill *et al.*, 2004; Shier, 2001). Public involvement in health research has also been defined as a continuum with three points: consultation, collaboration and user-control (Hanley, Bradburn and Barnes, 2004). In this sense consultation is about asking for children and young people's views on health research, collaboration is an ongoing partnership between researchers and children and young people, and user-controlled is when children and young people are fully engaged in and in control of the research (Fleming and Hudson, 2009, cited by Fleming & Boeck, 2012). Although this distinction between consultation, collaboration and user-controlled research is perhaps overly simplistic and now less commonly used, it does illustrate a similar distinction in health research between consultation and the 'genuinely participatory practice' this study sought to understand and embed.

The definition cited at the start of this section focuses on participation as a process but lacks emphasis on impact; it also places the emphasis on the input of individual children and young people without explicitly acknowledging the role of organisational cultures and processes in enabling change to happen (Tisdall *et al.,* 2014). Others agree that organisational cultures and processes are central to embedding participation (Kirby *et al.* (2003), as is establishing a shared understanding of participation (Wright *et al.*, 2006). But there is a lack of evidence on how this might happen in practice, for example Nolas (2015) suggest that there are many unanswered questions about the context and mechanisms which support effective participation, as well as *"a need for theoretical and empirical renewal in how children's participation…is understood and practiced"* (Nolas, 2015, p.160). A key focus for learning in this study therefore was to consider how understandings of participation, cultures, processes and practice enabled or created barriers for participation.

2.2.2 Typologies of children and young people's participation

The case for children and young people's participation is well established (e.g. Kirby *et al.*, 2003; Percy-Smith and Thomas 2010), but it is a multi-layered (Sinclair, 2004) and sometimes contested concept (Lansdown, 2006; Shaw, Brady and Davey, 2011) as outlined above. A number of typologies have been influential both in promoting children and young people's participation and documenting where it is lacking (Tisdall *et al.*, 2014). These typologies have in turn informed a wide range of models, toolkits and 'how to' guides, although the theory and models underpinning the practice of participation often appear confused and contradictory (Malone and Hartung, 2010; Thomas 2007). In his paper on moving *"towards a theory of children's participation"* Thomas (2007, p.199) draws on both political and sociological theory to delineate some of the potential components of a theoretical framework for children and young people's participation. This includes considering how and when children and young people participate, accommodating *"new kinds of participatory practice"* and understanding institutional context and processes *"and the cultures and dispositions that underpin them"* (Thomas, 2007, pp.215-216). Children and young people's participation in the UK still tends to focus on adult-initiated participation within a formal setting (Malone and Hartung, 2010). This means there is a risk of tokenism when children and young people taking part or being present is mistaken for the transfer of power and real influence on decisions (McNeish, 1999), suggesting a depoliticization of children's rights and participation (Nolas, 2015). I was therefore interested in ideas of children and young people as change agents and active citizens, and how this could inform more collaborative and young person-centred participatory practice (Malone and Hartung, 2010; Percy-Smith, 2016), discussed further in 2.4 below.

Many models of children's participation make distinctions between levels of participation according to the degree of power that is shared or transferred. Arnstein's (1971) ladder of citizen participation was adapted by Hart (1992) to include children and young people. Hart's (1992) ladder is still central to much discussion about children and young people's participation, with many typologies aiming to either refine Hart's model or set themselves apart from the implication that 'full empowerment' as the ultimate aim of participation (McNeish, 1999; Thomas, 2007). For example Kirby *et al.* (2003) argue that the type of participation activity should be determined according to circumstances and the participating children and young people, and that therefore no level of participation is 'better' than another. Likewise, Alderson (2001) proposes that good practice should mean that practitioners ascertain, and continue to check, the level of involvement desired by individual children and young people rather than assuming any level is inherently better. But Hart intended the ladder *as "a tool for thinking about children and young people's participation…[and] did not expect it to become a model for practice"* (Thomas, 2007, p.204). He argues that in fact the essential elements of the ladder are choice and different levels of support according to children and young people's developing competence (Hart, 2008). The key points for this study are that different forms and levels of participation may be appropriate in different circumstances and for different children and young people, but in thinking about this it is also important to consider the issues of power and control discussed in 2.4 below.

Participation is often framed as either at the level of individual decision-making or at a more strategic level (e.g. Kirby *et al.*, 2003). However this can be overly simplistic in relation to the realities of participation in practice. McNeish (1999) makes what I think is a more a useful distinction between participation in individual decision-making, in service development and provision, in communities and in influencing policy. This echoes the 4Pi national involvement standards for mental health which make a distinction between participation in individual care; participation in communities; participation in services and participation in planning, commissioning and governance (Faulkner *et al.* 2015). This idea of different forms rather than clearly differentiated levels of participation is echoed by Wright *et al.* (2006) who argued that participation should be based on a circular rather than graduated model of participation, with four key elements:

- *"Children and young people's involvement in individual decisions about their own lives, as well as collective involvement in matters that affect them…*
- *A culture of listening that enables children and young people to influence decisions about the services they receive as individuals, as well as how those services are developed and delivered…*
- *Not an isolated activity, but a process by which children and young people are enabled to influence change within an organisation…*

- *Not a hierarchy where the 'aim' is to reach the top.. different levels of participation are valid for different groups of children and young people and at different stages of an organisation's development"* .(Wright *et al.*, 2006, p.9)

In addition to referencing individual, collective and strategic involvement this also brings in the idea of participation as a process which influences change and draws on the idea of non-hierarchical models discussed above. Wright *et al.*'s (2006) elements also acknowledge the role of organisational cultures and processes in enabling change to happen, unlike some of the definitions discussed above (Tisdall *et al.*, 2014). However there is still a lack of emphasis on impact and an implication that the scope for children and young people's influence is determined and controlled by adults.

While it may indeed be appropriate for the level and nature of participation to be determined by the circumstances of the children and young people involved the dominant structures for children and young people's participation in the UK, such as youth forums and school councils *"have been much more about providing opportunities for children to practice 'good' citizenship than about children's voices being heard and acted upon"* (Crowley, 2015, p.602). Cairns (2006) suggests that structures such as youth councils, parliaments, deliberative forums, advisory groups and panels fall within the model of representative democracy (working with small groups of children and young people as representatives of a wider population) rather than participative democracy (creating opportunities for children and young people *"to be participants on their own behalf"* (p.222)). While such structures can certainly be effective ways for children and young people to influence decision-making they are, essentially, about adult-led and context-specific participation rather than supporting children and young people's individual and collective self-empowerment in ways which challenge adult-child power relations (Davis and Hill, 2006). That is not to say that models of participative democracy are necessarily better or more appropriate than representative democratic models, but rather that here is a need *"to pay closer attention to who is participating, in what and for whose benefit"* (Cornwall, 2008, p.269), and furthermore *how* they are participating. In this it is helpful to draw not just on participatory principles but on the emancipatory principles of disability studies, at the centre of which *"is the idea that projects are only worthwhile if they lead to real change in the life conditions of disabled people"* and facilitate processes through which *"people are able to achieve self-emancipation"* (Davis, 2011). Strategic participation of children and young people in health services and research tends to be through formal structures such as forums or advisory groups. However there is a need to consider whether these structures are necessarily always the best ways to involve children and young people, and who they may exclude. But on the other hand this assumes that all children and young people will want to participate, given the opportunity to do so, and that they have a

sufficient understanding to be able to make such decisions. Who chooses not to participate and why was an important consideration for this study, along with how best to involve those young people who want to be involved.

In addition to being framed as at the level of individual or strategic decision making (e.g. Kirby *et al.*, 2003) participation can be constructed as individual or collective, as when McNeish (1999) talks of participation in service development and provision meaning *"the involvement of young people individually or collectively as consumers of services"* (p.194). The dominant structures for strategic participation discussed above are generally collective, in the form of ongoing groups. But the distinction between collective and strategic participation is little discussed and possibly under-theorised in the literature on children and young people's participation (Thomas, 2012). Strategic participation can be individual as well as collective, and this study found that doing so may indeed enable some children and young people to participate who would not otherwise be able to do so. This study sought to understand the purpose and meaning of different forms of participation for young people and the adults and institutions seeking to engage them (Cairns, 2006), as well as considering the dynamic between collective and strategic participation.

2.2.3 Participation in health research

Involving those who are the focus of research has been found to have a positive impact on what is researched, how research is conducted and the impact of research findings (e.g. Brett *et al.*, 2014; Staley, 2009). The case for children and young people's participation in research has been explored in a number of publications (e.g. Alderson, 2001; Kirby, 2004; Kellett, 2005). The demand is that such research is carried out in a way that children and young people, as opposed to their parents or service providers, are listened to and heard (Roberts, 2010). In a review of children's engagement in health research (research either on children, with children or by children), Clavering and McLaughlin (2010) discuss how each approach involves some form of adult mediation and suggest that:

> *"Inclusion of children's perspectives can be achieved, at varying levels, in each approach (on, with and by)...Although claims to authority around including children's perspectives may appear to hold more credence when children have directly participated in the research, there may be times when this is neither possible nor appropriate".* (Clavering and McLaughlin, 2010, p.1).

In a similar vein colleagues and I have suggested that:

> "*...research which actively involves young people, if used to inform decision-making or policy formulation, could lead to policies and services that reflect children's priorities and concerns, although evidence for this is currently limited. In organisations where participation is not already developed involving children in research could help to promote a more participative culture.*" (Brady *et al*, 2012, pp. 230-231)

However there is a lack of evidence on children and young people's participation in health research (Bird, Culley and Lakhanpaul, 2013; Wilson *et al.* 2015). Much of the limited but growing literature focuses on the benefits, impact and outcomes of participation (e.g. Fleming and Boeck, 2012; Moules, 2005) and lacks a clear theoretical framework locating these methods in relation to *"the beliefs and assumptions researchers hold in relation to children, including their competence, rights and role within the research"* (Dockett, Einarsdottir and Perry, 2011, p.69). This links to wider criticisms of much public involvement in health research lacking a clear theoretical base (Beresford, 2013; Gibson, Britten and Lynch, 2012) as well as how much participatory research with children and young people has often gone uninterrogated by critical reflection (Richards, Clark, and Boggis, 2015).

Children and young people's participation in research is also an area where discourses of children's rights (having their views taken seriously) and the sociology of childhood (respect for children and young people's agency) overlap (Dockett, Einarsdottir, and Perry, 2011). Dockett, Einarsdottir, and Perry (2011) further argue that a focus on the purpose of participation as well as the methods is more likely to result in acknowledgement of children and young people's agency, as well as the development of that agency through children and young people gaining skills and knowledge. But in accounts of children and young people's involvement in health research children's rights are often mentioned (e.g. Jamal *et al.*, 2014; Mawn *et al.*, 2012) but without doing much more than referencing the CRC and stating that children and young people have a right to have a say in matters that affect them, including in research. Similarly typologies of participation are rarely discussed in any depth in the literature on children and young people's participation in health research. This suggests that, as proposed by Kellett (2010) children and young people's participation in health research can be tokenistic and poorly conceptualised, with assumptions unexamined as to whether, when and why the idea of children as researchers is a seen as an inherently 'good thing' (Tisdall, 2012). There is a need to engage *"service users more fully in collaboration with professionals in processes of systemic learning for change"* (Percy-Smith, 2007, p.880). This relates to the wider culture of public involvement in health research, which has been criticised for a lack of a clear ideological basis (Beresford, 2013) and a focus on the mechanisms and methods for involvement rather than *"a more genuinely emancipatory framework…which incorporates cultural, political and social dimensions" (*Gibson, Britten and Lynch, 2012, p.535). Wilson *et al.* (2015) suggest six actions are required for public involvement in health research to have positive outcomes and impact: researchers and lay (public) representatives *"having a shared understanding of the moral and methodological purpose"* of the involvement; a key individual co-ordinating

public involvement, lay representatives *"having a strong connection with the target study population",* the whole research team being positive about public involvement and fully engaged with it; efforts to develop relationships established and maintained over time and involvement being evaluated in a proactive and systematic approach (Wilson *et al.*, 2015, p.v). But Wilson *et al.* (2015)'s actions, while certainly relevant to this study, do not explicitly address the competing agendas and power relationships which Dockett, Einarsdottir and Perry (2011) argue researchers need to acknowledge in order to respect children's agency as well as their rights. *"Having a shared understanding of the moral and methodological purpose of the research"* (Wilson *et al.*, 2015, p.v). is not necessarily the same as having a clear and shared ideology. Participatory research with children and young people can be underpinned by rationales ranging from genuine attempts at power sharing and collaboration to rather more tokenistic efforts (Tisdall and Davis, 2004), and this study sought to understand and make explicit the rationale for involving young people in a health research study.

2.3 Understandings of childhood and children's rights

2.3.1 Understandings of childhood

Conceptualisations of children and childhood influence practices and approaches towards them (Tisdall *et al.*, 2014). Childhood studies, and in particular the sociology of childhood challenged ideas of children and young people being apolitical adults-in-waiting, and instead developed paradigms of children and young people as social actors and childhood as a social space in which children and young people can and do have agency and are experts in their own lives (e.g. Alderson, 2013; Jenks, 2005; Mayall, 2015). In this discourse children and young people are seen as beings not becomings (Qvortrup *et al.*, 2009), competent to share their views and opinions (James and Prout, 1997) but also constantly changing and evolving (Kesby, 2007; Lansdown, 2006). But one of the challenges of taking a rights-based approach to children and young people's participation in health services in particular is that views of childhood and children and young people in health are based on developmental approaches which can be contradicted or challenged by sociological definitions of childhood (Coyne and Harder, 2011; Vis *et al.*, 2011).

Theoretical approaches to childhood have in the past been dominated by paternalistic ideas of children and young people as needy, incompetent and vulnerable (Moss and Petrie, 2002). Developmental psychology suggests *"that what children mainly do during childhood is develop towards adulthood [and the]…basic idea of developmentalism permeates policy-making and practice".* (Mayall, 2015, p.79). This is particularly evident in the idea that children and young people are above all to be protected and provided for in order that

they may develop well and be prepared to enter into the public domain upon reaching adulthood (Mayall, 2015). In health services both parents and health professionals often *"take a protective stance towards children to act in their best interest"* (Coyne and Harder, 2011, p.12). Such stances may, as Vis *et al.* (2011) suggest, be based on ideas about children and young people's competence or adults taking the view that children and young people's participation in decision-making processes is potentially disruptive to their well-being. But parents and health professionals do have duties to protect and provide developmental opportunities for the children and young people for whom they are responsible. The challenge for children and young people's participation is when adults impose their own perspectives, consciously or unconsciously, on children or have different perspectives on what is in a child or young person's best interests (Ehrich *et al.*, 2015). If the child's views are seen as less important, or less valid, than adults' views this will influence practices and approaches towards them.

2.3.2 Children's rights and the CRC

The growth of sociological interest in children and young people has coincided broadly with the development of the modern children's rights movement (Mayall, 2015; Qvortrup *et al.*, 2009). But Freeman (1998) suggests that there has, until relatively recently, been surprisingly little overlap between the two. Children's rights both in relation to decisions about their own health care and concerning the development of services are underpinned by the CRC (UN, 1989), ratified by the UK government in 1991. The CRC encompasses social, economic, civil and political rights, and *"asserts children's right to have a voice in decision-making, as well as rights to freedom of thought and expression"* (Percy-Smith and Thomas, 2010: 1). The key article relating to participation, Article 12, states that:

> *"States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." (UN, 1989).*

Children's rights apply to children and young people as individuals and as a constituency (i.e. representing other children and young people, for example as an advisory group). A key implication of Article 24 of the CRC is that all children and young people have needs that must be met in order to optimise their health and wellbeing:

> "*States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services"* (UN, 1989)

In a General Comment on Article 24, which sets out how that article should be interpreted by signatories to the CRC, the UN Committee on the Rights of the Child emphasised *"the*

importance of approaching children's health from a child-rights perspective" (UN, 2013, p.3) and stated that:

> *"Article 12 highlights the importance of children's participation…This includes their views on all aspects of health provisions, including, for example, what services are needed, how and where they are best provided, barriers to accessing or using services, the quality of the services and the attitudes of health professionals, how to strengthen children's capacities to take increasing levels of responsibility for their own health and development, and how to involve them more effectively in the provision of services, as peer educators. States are encouraged to conduct regular participatory consultations, which are adapted to the age and maturity of the child, and research with children, and to do this separately with their parents, in order to learn about their health challenges, developmental needs and expectations as a contribution to the design of effective interventions and health programmes"* (UN, 2013, p.7).

This quotation sets out in far more detail than the CRC itself what these children's rights under Article 24 mean for their participation in health services and research both within decisions about their own care and in collaborative and strategic participation. It also highlights what the UN Committee thinks successful participation in health services and research might look like in practice. But although the CRC recognises children's right to health and addresses many rights contributing to that right to health (including participation) it is not on the UK statute and therefore includes:

> *"…both substantive limitations on the scope of those rights and procedural limitations on the ability of individuals and other parties to enforce those rights against states parties"* (Reinbold, 2014, p.14).

The realisation of children's rights to health, and to participation, requires their translation into policy and practice; as well as children and young people's participation in conceptualising and realising these rights (Spronk, 2014).

Childhood studies, and an associated affinity with children's rights, have promoted a rethinking of children's status and agency. This has in turn informed a policy and practice agenda which incorporates the traditional protection of children with introduction of rights of participation (Tisdall, 2012). A rights-based approach *"shifts the construct of children from individuals having needs to persons with entitlements to have their needs met"*, by acknowledging that they are the *"subjects of rights…with the capacity to influence matters of concern to them"* (Lansdown, Lundy and Goldhagen, 2016, p.253).

2.3.3 Which rights and for whom?

Children's rights are about more than children and young people's right to have a say in matters that affect them; the CRC recognises that children and young people *"also have particular needs and vulnerabilities that require special protection beyond the rights to which adults are entitled"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.6). The CRC also sets out the responsibilities of adults to provide guidance to children and young

people and to protect them from harm (McNeish, 1999). Participation rights do not operate in a vacuum and the UN General Comment on Article 24 quoted above emphasises the interdependency of children's rights. There is a further argument that rights-based arguments for young people's participation should not be accepted at face value, with the suggestion that *"the primary emphasis within the field of Childhood Studies has been upon autonomy or participation rights"* (Hammersley, 2015, p.572) as opposed to welfare or socioeconomic rights":

> *"However…while the UNCRC does assign some autonomy rights, these are framed by an overarching concern with 'the best interests of the child', those interests not being treated as identical with a child's desires or preferences…Furthermore, the autonomy rights that the UNCRC grants are explicitly constrained by judgments on the part of adults as regards the competence of the children concerned" (Hammersley, 2015, p.572)*

Tensions inherent in the CRC between participation, protection and provision rights can be particularly acute in relation to children and young people's health (Alderson, 2014; Franklin and Sloper, 2005) and between children's rights and wellbeing (Tisdall, 2015). Healthcare practitioners may perceive a need to balance children's rights and clinical responsibilities (Schalkers *et al.*, 2016). Although the last thirty years *"have seen growing support for the idea of children as social participants in their own right, this has not been without opposition"* as children and young people have tended to be thought of by policymakers as *"objects of concern"* rather than *"persons with a voice"* (Hallet and Prout, 2003, p.1). Tensions between provision and protection rights and participation rights can be particularly acute in relation to children and young people's participation in decisions about their individual care as healthcare organisations are:

> "*often steeped in welfare principles which view children as essentially vulnerable and lacking competence and adults as responsible for their care and protection"*
> (McNeish, 1999, p.193)

Decisions about health are therefore still often imposed by professionals rather than made by or with children and young people, despite increasing commitment to user involvement in health services (Percy-Smith, 2007). Woodhead (2010) questioned whether the focus of much of the discussions on children's rights on participatory rights as opposed to provision and protection rights can be misleading or even dangerous. In health services in particular protection and provision rights can both undercut and enhance participation rights:

> *"The health service has a child's survival and development rights as its key focus, but all those working with children within a service need to ensure children's rights to protection and participation are also given equal consideration…in the context of children being part of a wider society that also has needs and rights*".
> (Jones and Welch, 2010, p.167)

This consideration of competing or complementary rights and the implications for children and young people's participation in health services and research was an important

one for this study. Conceptualisations of childhood and their relation to children's rights in relation to health services have particular resonance for young disabled people. Disabled children and young people are considerably less likely than their non-disabled peers to be in involved in decisions about their own care and about service development (Franklin and Sloper, 2009). Both childhood and disability studies have positioned themselves as counter-paradigms to previous, paternalistic paradigms where children and disabled people were marginalised and *"deemed insufficiently competent and rational to take up their roles as citizens and contributors"* (Tisdall, 2012, p.183):

> *"Just as childhood studies has sought to re-conceptualise children and childhood, disability studies a decade earlier sought to re-conceptualise disabled people and disability. Such re-conceptualisations were not only theoretical, but closely aligned with the disability rights movement — just as childhood studies, and particularly its focus on children as active agents and social actors, links with those promoting children's rights in policy and practice".* (Tisdall, 2012, p.182).

Childhood studies has been criticised for focusing on participation as opposed to welfare rights and therefore:

> *"undercut[ting] the notion of welfare and protection rights for children by denying that childhood involves distinctive biological features, or by downplaying the significance of these* (Hammersely, 2015, p.575).

Disability studies have played an important role in critiquing the normative impacts of childhood studies' focus on 'child first' and an often homogenous view of children, leading to the emergence of disabled children's childhood studies as a distinct approach (Curran and Runswick-Cole, 2014). Although disability studies is not a primary focus for this study, these debates and developments are nonetheless important in considering how a rights-based approach informed both my research approach and the topic of study. There is a danger that in framing 'young people' as a homogenous group research and practice an unintentionally marginalise those who are less frequently heard or need additional support to participate. I therefore sought to pay particular attention in this study to who was and was not involved, and to identifying the barriers and enabling factors to inclusive participation in my case studies. As Hammersley (2015) points out*: "rights-based arguments require scrutiny…[and] should not be accepted at face value"* (p.569). But, although conceptions and understandings of the implications of rights certainly need to be explored rather than unquestioningly accepted I agree with Lansdown and colleagues that:

> *"..the CRC and associated principles of child rights provide strategies for rights-based approaches to clinical practice and health systems, as well as to policy design, professional training, and health services research"*
> (Lansdown, Lundy and Goldhagen, 2016, p.265).

It is on this basis that I approached this study: considering if and how a children's rights - based approach can support the embedding of young people's participation in health services and research.

2.4 Citizens or consumers?

2.4.1 Citizenship

Young people's participation in health services and research need to be seen in the broader context of the service user involvement movement and public and citizen participation (Beresford, 2012). Children and young people's participation in health services takes place within the context of social movements which over the last three or four decades have emphasised "*the limitations of a biomedical model in promoting health and illness [and called]…for more shared models of treatment and decision-making"* (Ocloo and Matthews, 2016, p.3). But there is an additional power dimension in that much of children and young people's participation is still initiated and led by adults, and there are many debates about the power dynamics in this context (Alderson, 2014; Percy-Smith, 2010; Thomas, 2012). The UN General Comment on CRC Article 24 (UN, 2013) still suggests participation which is primarily adult-led and involving children and young people in adult power-structures. But participation is not just something that happens when adults invite children and young people to come along and give a view (Cockburn, 2005; Wyness, 2013). Marshall (1997) suggests that participation rights under the CRC are often misinterpreted as *"a power to control",* rather than children and young people's right to make a contribution to the decision-making process. But conversely:

"*…the majority of [public] involvement activity in healthcare has traditionally taken place at the level of feedback and information-giving…[with patients] struggling to influence decisions…within existing systems….[which] serves to maintain professional and system interests and power."* (Ocloo and Matthews, 2016, p.4)

The ideas of meaningful participation and the tension between participation, provision and protection rights links back to the constructions of childhood and debates about children and young people's citizenship (James, 2011; Roche, 1999). Thomas (2012) suggests that in order to participate fully children and young people need to be respected as rights-holders, but also for there to *be "mutual esteem and solidarity, and a sense of shared purpose"* (p.463). However there are *"inequalities and injustices in the way power is exercised and decision-making controlled by adults"* (Percy-Smith, 2016, p. 401). The sociology of childhood draws our attention to the positioning of children and young people in society relative to adults, their citizenship status and their capacity to participate fully as members of society (Cockburn, 1998; Devine, 2002). Lister (2007, p.694) argues

that *"the language of citizenship has a contribution to make over and above that of rights".* Citizenship can be constructed as both an expression of human agency and as a right enabling children and young people to act as agents, rather than a legal status alone (Lister, 2007). As well as emphasizing individual rights, citizenship discourses highlight the collective agency of children and young people through recognition of common issues (Dockett, Einarsdottir, and Perry, 2011), and activity *"characterised by agency on the part of young people, as well as collective action towards social change"* (Shaw *et al*., 2014). Devine (2002) proposes a theoretical framework which highlights the interrelation between structure (typifications of children and young people as citizens with particular rights or 'other') and the power and agency of children and young people in institutionalised practice. Contrary to assumptions about children and young people's competence to participate, and in spite of their marginalisation within society, children and young people:

> *"…are in reality already participating de facto as active citizens within the spaces of their everday lifeworlds"* (Percy-Smith, 2016, p.403).

Such *"informal active citizenship"* provides an alternative to *"adult decision-making according to the agenda, priorities and initiatives of adult professionals",* in which children and young people are able to participate *"in spaces of their choosing and in ways they decide…as active citizens"* (Percy-Smith, 2016, p.413). The relationship between understandings of childhood, children's rights, citizenship, power and organisational practice are central to the embedding of children and young people's participation in practice and constitute a key focus of this study. This study sought to address these issues in relation to how, when and by whom opportunities for young people's participation are created in health services and research, as well as the level and nature of the opportunities provided.

2.4.2 Patient choice and consumer rights

Children and young people's citizenship in relation to health services requires consideration of whether the focus on choice, competition and service improvement within the National Health Service (NHS) and other public services equates consumers' rights with citizens' rights (Plamping and Delamothe, 1991). The introduction of market reforms has encouraged users of NHS services to adopt the same consumer values and expectations apparent elsewhere in society (Sturgeon, 2014). Ideologies of democratic public engagement and *"an economically motivated 'consumer approach' aiming at greater efficiency"* have underpinned participation initiatives in the health sector ranging from improving choice in relation to individual treatment to involving members of the public in the redesign of services (Gibson, Britten, and Lynch, 2012, p.532). Patient choice has become, at least rhetorically, central to health policy in the UK (Fotaki, 2014; Ocloo and

Matthews, 2016). But others have argued that the Health and Social Care Act (2012) and associated changes to health commissioning:

> *"undermines the principle of patient and public involvement, public accountability and returns the power for prioritisation of health services to an unaccountable medical elite".* (Tritter & Koivusalo, 2013)

Tensions have also emerged between ideas of patient choice (that is consent to or refusing treatment options chosen by a health professional) and consumerist choice (changing the locus of responsibility from the professional to the patient as consumer), with the latter implying that the professional becomes *"simply an agent of the patient's demands" (*Downie and Randall, 2008, P.182*).* Furthermore the wider service user involvement movement has *"been a complex mixture of state and service-user-led initiatives"* which call into question the traditional division of life into public and private spheres and often frame rights in a political context (Beresford, 2012, p.33). Beresford (2013) outlines two particular ideological approaches which he says have underpinned modern developments in user involvement: the managerialist/ consumerist approach and the democratic or empowerment model. The first is developed by the state and services with an emphasis on *" drawing in the views and ideas of the public and service users as consumers or customers" in order to inform the evidence-base for "rational decision-making"* by services (p.144). The second, the democratic or empowerment model:

> *"....[is] developed by service users and their organisations and concerned with increasing their say, redistributing power and ensuring them involvement in decision-making. These two are very different approaches ... that have underpinned the development of user involvement more generally in policy and practice. Both approaches, managerialist/consumerist and democratic are inherently political, but the former tends to be abstracted and treated as technical, as if it were unrelated to any broader ideology or philosophy. The democratic approach is explicitly political"* (Beresford, 2013, p144).

However while it is important to locate this study in the context of these wider debates, critiques of patient choice in the NHS tend to be adult-centric and imply a confident, informed and assertive body of 'consumers' which do not reflect the way in which children and young people (and arguably also other 'vulnerable' groups including disabled and older people) are seen and treated within the NHS. Those groups who may have particular or even greater healthcare needs than the wider population, and therefore have most to gain from participation, can often be those *"most excluded from healthcare decision-making"* (Ocloo and Matthews, 2016). Children and young people who *"due to a combination of their circumstances and lived experiences come to be identified as 'vulnerable' or 'disadvantaged'"* are likely to experience more barriers to participation while conversely being those that health organisations may be failing to reach (McNeish, 1999, p.200). Children and young people deemed to be 'vulnerable' may also be denied the opportunity to be involved in health research because of this perceived vulnerability

(Berrick, Frasch, and Fox, 2000). However this was challenged in a Nuffield Council on Bioethics report which suggested children and young people should be protected *through* clinical research rather than *from* it (Nuffield, 2015). In taking a rights- and citizenship-based approach to children and young people's participation in health services there is a need to consider:

> *"How best to provide [health] services that address the demands and needs of children? How to redress the history of health services for children being primarily based on adult services and perceptions?"* (Jones, 2011a: 28)

It is important to locate children and young people's participation in health services and research within the wider debates about public engagement, consumer rights and patient choice. But it also important to understand that, as Jones (2011a) points out, these debates are primarily based on adult services and perceptions; children and young people face additional challenges in relation to power and agency in institutionalised practice.

2.5 Developing a participatory framework

2.5.1 Theoretical frameworks

A theoretical framework establishes *"a set of strategic values within which individual researchers can anchor the tactics required in their everyday practice"* (Christensen and Prout, 2002, p.477). It provides *"connections between theoretical perspectives, research strategy and design, fieldwork and the conceptual significance of the evidence"* (Leshem and Trafford, 2007, p.99). But although children and young people's participation has been informed by a wide range of theoretical sources, it *"lacks its own distinctive theoretical basis"* (Thomas and Percy Smith, 2010, p.3). The task of theorising children and young people's participation can be conceptualised as:

> *"(1) analysing what is meant by participation, (2) understanding what happens when children participate and (3) a normative account in terms of the ethical purpose of the activity*" (Thomas, 2012, p.462).

Theoretical frameworks incorporate epistemology, ontology and methodology to establish strategic values which anchor the research in relation to:

> *"…the beliefs and assumptions researchers hold in relation to children, including their competence, rights and role within research…reflecting on these beliefs and assumptions provides a basis for the practice of research."* (Dockett, Einarsdorrit and Perry, 2011, p.69)

In seeking to understand what it means to embed participation I considered how organisational systems and processes could support or create barriers to young people's participation. McNeish (1999) argues that it is important to:

> *"…consider the context in which participation is sought. Within many health and social care settings full empowerment may be neither feasible nor desirable. Honest and realistic parameters for participation need to be established according to the nature of decisions to be made"* (p.193)

Argyris and Schon (1996) and Popper (1979, 1999) propose that knowledge in organisations comes from learning stimulated by a perceived problem. In their theory of organisational learning Argyris and Schon (1996) suggest that most organisations only undertake 'single loop learning' which leaves the values and norms underpinning action unchanged; they developed a theory of double loop learning which promoted inquiry, challenged current assumptions and actions and led to more robust knowledge. This study sought to open up to critical inquiry existing assumptions and practices concerning participation, and to understand the systemic arrangements required for young people's participation to be embedded effectively.

2.5.2 Participatory frameworks in practice

There is as yet little evidence of the changes required in services and organisations to embed participation as a process and culture of learning and change as a matter of course in service settings. The focus of this study on the reality of participation in practice means that consideration also needs to be given to frameworks and toolkits on children and young people's participation in the grey literature.

'Hear by Right', a participation approach and toolkit, draws on the 'seven S model' of organisational development involving shared values, strategies, structures, systems, staff, skills and style of leadership (AYPH, 2010; Badham and Wade, 2008). This suggests that embedding children and young people's participation needs to involve an organisational culture for learning and change. This study was informed by the whole systems approach first suggested by one of my case studies. This approach identifies the various components of a system and assesses the nature of the links and relationships between each of them (Burns, 2007). It can be a useful way of building a culture of participation by enabling the organisational change necessary for meaningful participation, enabling participation to become part of daily practice and involving service users in different levels and different types of decisions (Kirby *et al.*, 2003). Wright *et al.*(2006) suggest that different elements of children and young people's participation in social care could be brought together in a single framework which considers culture, structure, practice and review. These elements are presented as four interconnecting pieces of a jigsaw. Culture is defined as *"the ethos of an organisation, shared by all staff and service users which demonstrates a commitment to participation"*. Structure is *"the planning, development and resourcing of participation evident in organisation's infrastructures"* . Practice *"the ways of working, methods for involvement, skills and knowledge which enable children and young people to become involved"* . Review is *"the monitoring and evaluation systems which enable an organisation to evidence change affected by participation"* (Wright *et al.,* 2006, p.12). The model aims to

bring together the overarching themes from the literature on children and young people's participation, so synthesizing rather than replacing existing models:

> *" [By] considering these four components of service development and delivery, children's participation is more likely to result in change or improvement of … services"* (Wright *et al.*, 2006, p.12)

However Wright *et al.* (2006) clarify the meaning of participation principally in relation to the context in which it is employed in their research or guidance (i.e. state their working definition of participation). Therefore although Wright *et al.*'s (2006) model provided a starting point for my thinking about what it means to embed participation, I sought to build on it by exploring how participation is understood by those who work with children and young people, and how these understandings may affect participation cultures and practice.

The starting point for Wright *et al.*'s (2006) model was organisational systems, structures and processes, rather than the alternative child-initiated ideas of children and young people as change agents and active citizens discussed by Malone and Harburg (2010), Percy-Smith (2016) and others. The balance of power in many healthcare organisations also tends to *"favour the organisation or system, rather than partnership working with patients and the public"* (Ocloo and Matthews, 2016, p.4). In addition to considering how organisational systems and processes could support or create barriers to young people's participation my theoretical framework also draws on the ideas of children's rights, citizenship, public involvement and paradigms of participatory research discussed in this and the preceding chapter. Heron and Reason (1997) define participatory paradigms as including a focus on a social or political agenda for reform that may change the lives of the participants, their institutions and the researcher themselves. Participatory research also centres on practical and collaborative action conducted 'with' rather than 'on' others, and a participative, subjective reality (Creswell, 2007; Guba and Lincoln, 2008). A participatory paradigm focuses on the needs of groups and individuals who may be marginalized in society (Maconochie, 2013). Given that the focus of this study was participation, my epistemological and methodological approaches sought to reflect the subject (Thomas, 2002). Rather than simply identifying issues this study was underpinned by an intention to engage young people alongside professionals in *"making sense of their views, experiences and priorities"* in relation to participation in health services and research, and *"consider different actions and choices within the context of current…service provision"* (Percy-Smith, 2007, p.880). As discussed further in 4.1 I therefore took a participatory approach:

> *"…within which there is a social contract, that honours and values the multiple voices and perspectives of those who take part… [and] where adults, children and young people work in partnership with each other".* (Groundwater-Smith, Dockett and Bottrell, 2015, p.22)

Child rights-based research emphasises using the process of research to promote children's rights by using a participatory approach (Boyden and Ennew, 1997; Beazley and Ennew, 2006). Johnson (2010) sets out a series of preconditions which she believes should be considered when considering whether evaluation can fit into a rights-based framework which I sought to apply in this study, including:

> *"…leav[ing] space for methods to change, transparency in agenda and objectives and honesty about dilemmas in implementing children's participation in a real world of barriers and constraints…At the core…lies the belief that children's participation is invaluable in understanding how projects and services can be most effectively delivered and that without their perspectives pieces of the jigsaw are missing"* (Johnson, 2010, p.162).

This echoes my feeling, as discussed above, that by focusing on organisational systems, structures and processes Wright *et al.*'s (2006) jigsaw model is missing a piece: the perspectives of young people are only implicit. By contrast Lundy's (2007) model of participation aims to provide a way of conceptualising a child's right to participation, centred on Article 12 of the CRC as a means of *"informing understanding, developing policy and auditing existing practice"* (p.12). Lundy's model has four elements: space (safe, inclusive opportunities to form and express views), voice (facilitating children to express their views), audience (listening to children's views) and influence (acting on views as appropriate). Seymour's (2012) 'Good Practice Principles for Youth Development Organisations' also state that *"youth development organisations and programs [should]…be youth centred and work in partnership with young people"* (p.5).The theoretical framework for this study is underpinned by these principles of rights and young person-centred working.

Jones and Welch (2010) point out that *"concepts and practices related to child rights cannot, or should not, be accepted uncritically"* (p.6) and that any work with a child rights focus also needs to engage with social, economic and political concerns relevant to CYP's inclusion and diversity. This study sought to open up to critical inquiry existing assumptions and practices concerning young people's participation, in particular to ask whether children's rights are an essential pre-condition for participation to be embedded in health services and research, as discussed in 2.3.2 with reference to the UN General Comment on Article 24.

2.6 Conclusions

This chapter sought to locate the study within the wider literature concerning participation and childhood, and consider how these are informed by debates around children's rights, citizenship and agency in relation to their participation in health services and research. Children and young people's participation is a popular concept in many healthcare organisations and in health research, but the terminology can be opaque and describe different activities in varied circumstances. There tends to be a focus on mechanisms and methods rather than theoretical and conceptual frameworks. There is also limited understanding of how the terminology and ethos of participation informs participative practice and the role organisational processes and cultures can play in enabling or creating barriers to participative practice. This study builds on the literature outlined in this chapter to explore young people's participation in relation to individual and collective as well as individual and strategic participation, and how different models and approaches to participation worked in practice for young people and professionals in two case studies. The relationship between understandings of childhood, children's rights, citizenship, power and organisational practice appear to be central to the embedding of young people's participation in practice. The literature also suggests that any work with a child rights focus also needs to engage with social, economic and political concerns relevant to CYP's inclusion and diversity, and to do so with a critical perspective on the implications of a rights-based approach to practice, and the interplay between participation and welfare rights. All these issues highlight gaps between the rhetoric of participation and the reality of professional practice and young people's experience which this study sought to explore.

Dockett, Einarsdorrit and Perry (2011) outline how a theoretical framework should establish strategic values in relation to *"…the beliefs and assumptions researchers hold in relation to children…[providing] a basis for the practice of research."* (p.69). This study sought to understand how organisational culture, systems and practice support or create barriers to young people's participation, and to locate this within a framework of participatory, rights-based research (Boyden and Ennew, 1997; Beazley and Ennew, 2006). The study is therefore underpinned by a participatory paradigm through which I sought to engage in practical and collaborative inquiry in order to understand what is necessary for young people's participation to be embedded in health services and research. Chapter 4 outlines further how this theoretical framework informed the study methodology and methods, but first I turn my attention to the evidence for the application of this theoretical framework in legislation, policy and practice.

3. Children and young people's participation in health policy and practice

The previous chapter explored interpretations and typologies of participation and childhood, and how these are informed by debates around children's rights, citizenship, agency and organisational practice. This chapter considers the evidence for the application of these theoretical understandings in legislation, policy, and the practice of children and young people's participation in health services and research.

3.1 The legislative and policy context for children and young people's participation in health

The understanding that children and young people should be involved in decisions which affect them has been increasingly reflected in UK law, guidance, regulation and policy in relation to health (Franklin and Sloper, 2005). There have also been repeated calls to involve patients and members of the public in healthcare improvement in response to serious clinical and service failings in the UK and internationally (Ocloo and Matthews, 2016). In their response to the Children's Health Outcomes Forum (Department of Health (DH), 2012) the English government acknowledged the importance of children's rights and the CRC being at the heart of health and social care (DH, 2013a). Patients working in partnership with clinicians and carers in decisions about their healthcare is one of the guiding principles of the NHS Constitution (DH, 2013b). The 2013 Chief Medical Officer for England's Report talked about the expectation inherent in the Constitution*:*

> *"that patients, service users and the public participate nationally and locally in the development, implementation and accountability processes of health and social care policy and services…This expectation for patient and public participation has no age limit. Children and young people…should be encouraged and facilitated to participate in decisions about their own care and, more broadly, about the health and social care services and policies that affect them".* (DH, 2013c, ch4, p.2).

English legislation and policy have to some extent reflected these expectations: the *Children and Families Act* (2014) mentions children's rights and the CRC, and public involvement is a key element of the *Health and Social Care Act* (2012). Alongside these there has been increasing awareness of the importance of developing children and young people's participation in health services in a strategic and systematic way (e.g. National Youth Agency (NYA), 2010; Association for Young People's Health (AYPH), 2010; DH, 2013a; Redsell and Hastings, 2010). Within health services there has been increased use of rights-based tools and quality criteria such as 'Hear by Right' (Badham and Wade, 2008), 'You're Welcome' (DH, 2011) and 'Young People-Friendly' (4YP, 2013). Internationally the Council of Europe Guidelines for Child Friendly Healthcare set out three levels at which children and young people should be provided with opportunities for participation: individual decision making, providing feedback on their experience of services, and in the

policy-making and planning processes of the health services they use (CoE, 2011). World Health Organisation guidance on adolescent friendly health services also emphasise the importance young people being *"well informed about [health] services and their rights… [and] involved in service assessment and provision"* (WHO, 2002).

But while the language of children's rights has been widely employed in law, guidance, regulation and policy there is a lack of evidence for whether and how these rights are enabled in practice, and whether this has necessarily always led to improved outcomes for children and young people (Ferguson, 2013), or on policy-making and service delivery (Byrne and Lundy, 2015; Crowley, 2015). There is also limited evidence for if and how available tools, guidance and criteria have supported the embedding of children and young people's participation in health services (Weil *et al.*, 2015).

3.2 Professional practice

It is now generally considered good practice to involve children and young people in decisions about the healthcare they receive:

> *"Health professionals should act as patient advocates and ensure the participation of children and young people in all aspects of decision making [that affect them]. This should be seen as the norm. If children are excluded from decision making, there must be justification for that stance".* (BMA, 2001, p. 229).

Children and young people's participation is becoming more common in paediatric health services and there is some recognition that:

> *"Issues which are fundamental to paediatric practice are at the heart of the [UN] convention: communication, explanation, protection, respect and participation. Knowledge of the convention helps the clinician enter…the world in which the child lives, is nurtured and develops."* (Waterston, 2012)

Webb *et al.* (2009) suggest that taking a rights-based approach to health services introduces paediatric professionals *"to new ways of thinking and being in respect of how we view and treat children"* (p.431), and potentially changes their cultural view of children and young people. Furthermore:

> *"Improving [paediatric] services in line with the [UN] convention requires action at all levels of an organization; it must embrace the commissioning and planning of services, both locally and nationally, operational policies, audit, management practices, as well as clinical guidelines and direct hands-on care".* (Webb *et al.*, 2009, p.431).

However in practice services for children and young people are often seen as the 'poor relation' to the adult services within the NHS (Evans, 2016). Even if some healthcare professionals and organisations are committed to participation others:

> *"…[may] feel threatened by the notion of active involvement. Though individuals, teams and organisations may be interested and deeply committed to involving patients and family members, they may lack clarity about what the issues are, who to involve and the goals of involvement."* (Ocloo and Matthews, 2016)

Despite the stated importance of children and young people's participation in legislation and policy their views are still not consistently sought or acknowledged within healthcare settings; they are rarely involved in decision-making process and often occupy a marginalized position in healthcare encounters (Coyne, 2008). There are inherent contradictions in commonly held beliefs and values held about children and young people's participation in health services, including assumptions about children and young people's competence, rights and vulnerabilities and adult responsibilities which are often unarticulated within organisations (McNeish, 1999):

> *"Participation has become a popular concept but the transfer of power and choice, which is necessarily associated with meaningful participation, often fails to occur. One reason for this may be that the predominant culture in most health and welfare agencies emphasises the vulnerability of young people"* (McNeish, 1999, p.194).

How willing health professionals are to actively involve children and young people in healthcare decision-making can depend on *"the type of decisions being made, the child's medical condition and his/her age"* (Schalkers *et al.*, 2016, p.1041). Since the last UN report (UNCRC, 2008) the English Government has introduced some measures including:

> *"...the reform of the Children's Commissioner, the Ministerial commitment to give 'due consideration' to the Convention on the Rights of the Child (CRC) and the statutory guidance to Directors of Children's Services, requiring them to have regard to the CRC General Principles and ensure children are involved in the development of local services... and the attempt at a child budgetary analysis"* (CRAE, 2015a, p.1).

However the Children's Rights Alliance for England report on UK implementation of the CRC (CRAE, 2015a) argues that the Government report to the UN (HM Government, 2014) failed to fully address the 20 recommendations made by the UN Committee (UNCRC, 2008), which aimed to ensure that all children and young people have all their rights respected with enforceable means of redress. While some aspects of the CRC had been replicated in UK legislation, the CRAE (2015a) report criticises the failure of successive UK governments to take forward the UN Committee's recommendation to expressly incorporate the CRC into domestic law, or as a statutory obligation in relation to the development of policy which affects children and young people. They suggest that this has resulted in a piecemeal approach which means that rights are dependent on where children and young people are located or what services they receive, rather than being the entitlement of every child without discrimination (CRAE, 2015a). As a result participation in health services is limited and patchy (Blades *et al.* 2013; RCPCH, 2010) and, *"particularly within service development, may only be occurring at relatively lower levels of decision-making"* (i.e individual rather than strategic), with a need for change and challenge if *"participation is to become embedded and sustained"* (Franklin and Sloper, 2005, p.24).

The target-driven cultures of public sector providers can also undermine attempts at participation through barriers such as inflexible bureaucratic structures, which may be at

odds with the priorities and concerns of children and young people (Percy-Smith, 2007). The values and ideologies of healthcare professionals, along with NHS organisational systems and processes, can create barriers to translating stated policy commitments to the involvement of the public in the NHS into embedded practice (Gibson, Britten and Lynch, 2012). Rather than being embedded in everyday healthcare practice participation often relies on individual professionals, with a focus on consultation with children and young people about their individual health needs rather than collaboration in the commissioning, delivery or evaluation of health services (Blades *et al.* 2013; Ocloo and Matthews, 2016). Children and young people are often *"generally excluded and not sufficiently involved in individual healthcare decisions…service improvement and policy-making"* (Ehrich, *et al.*, 2015, p.783).

Views of childhood in health tend to be based on developmental approaches which can be contradicted or challenged by sociological definitions of childhood and a rights-based approach (Waterston, 2012). This can create problems in the context of both on-going and short-term use of health services. For example, professionals' lack of knowledge of the preferences and experiences of young people with chronic conditions was found to create particular difficulties for young people learning to manage their own care while making the transition from paediatric to adult services (Jedeloo *et al*, 2010). Others have talked about the importance of participation for children and young people with long-term conditions such as chronic heart disease (Smith and Gray, 2009) and diabetes (Dovey-Pearce *et al.*, 2005). There is also a considerable literature on participation in Child and Adolescent Mental Health Services (e.g. British Psychological Society, 2001; Macdonald *et al.*, 2007). Children and young people attending emergency departments in England rarely have an active say in their assessment and treatment, despite evidence of the benefits to outcomes and children and young people's experience (Hemingway and Redsell, 2011). A report by the UK Children's Commissioners to the UN Committee further suggests that:

> *"…austerity measures have reduced provision of a range of services that protect and fulfil children's rights including health and child and adolescent mental health services"* (Children's Commissioners, 2015, p.2).

This is echoed by the CRAE (2015a) report, which found that due to reductions in public funding and a lack of coordination across health services, many children and young people in England are still not receiving healthcare when they need it or in an age-appropriate manner. There are also insufficient early intervention and community-based services and, possibly related to this, increased rates of children and young people attending Accident and Emergency departments (CRAE, 2015a). The importance of introducing the principles of participation and children's rights to students preparing for professional healthcare practice, and through ongoing training and support has been raised by several

commentators (e.g. Bennett and Race, 2008). The Children's Commissioners' report to the UN (Children's Commissioners, 2015) recommended that the UK government should do more to ensure that all children and young people are listened to and given clear information and explanations about their health, included in all relevant indicators in the NHS Outcomes Framework (DH ,2013a) and in all relevant patient surveys or other mechanisms for recording patient experience and complaints, to ensure that their voices inform commissioning and service development (Children's Commissioners, 2015).

In their assessment of how the CRC has informed the voices of children and young people in healthcare in the UK Weil *et al.* (2015) suggest that sustained progress in children and young people's participation requires change in four areas: greater dissemination of existing guidance, more evaluation of participatory processes and impacts, appropriate training, structures and procedures to support individuals and organisations with participation, and more support for children and young people to be involved in managing and improving their own health as well as improving health services (so individual as well as strategic participation).

3.2.1 Participatory practice

Recent national developments in participatory practice in health have included NHS England establishing a Youth Forum (NHS England, 2016), the introduction of new children's experience measures within the NHS, The Care Quality Commission involving children and young people in their inspection activities (CQC, 2016), and the involvement of children and young people on the board of Healthwatch England and within local Healthwatch bodies (DH, 2013c). NHS England has also organised a number of events bringing children and young people, policymakers and health professionals together, and 'young people's healthcare' was one of five priority areas discussed at the first NHS Citizens' Assembly (NHS Citizen, 2015). The 'CYP Me First' programme is also developing practice around child-centred communication in health services (CYP Me First, 2017).

In service delivery we can learn important lessons from another service in which, as the CCHP case study, young people and families were involved from the outset in the design and delivery of a multi-agency service which had participation at its heart and challenged the top-down nature of much participation in public services. The One Point Service in County Durham included as a partner a local children's rights organisation, Investing in Children (IiC), and *"attempted to avoid tokenism by stimulating fundamental change concerning the relationships between service user and provider"* (Davis and Smith, 2012, p.43). Another IiC project, Type 1 Kidz, developed a patient-led approach in collaboration with young people, which appears to improve the health and wellbeing of children and

young people with Type 1 diabetes by developing their capacity for self-management (Mulhearn and Brown, 2017). At the core of IiC's collaborative and relational approach is the notion that participation is not a single project, but a sustainable process (Davis, 2011) in which it is important to be clear about the aims, outcomes and structures underpinning participatory practice (Davis and Smith, 2012). This is echoed by another example of participatory practice, the Well Centre in South London, an adolescent health centre designed and developed by a general practice and a youth work charity. From the outset this service sought to engage in co-production with potential users and had an active young people's panel which had input into service design and delivery (Hagell and Lamb, 2016). Initial data suggested that the Well Centre was proving successful in finding new ways to engage *"a vulnerable group of young people who might otherwise have slipped through the health care nets"* (Hagell and Lamb, 2016, p.241).

As outlined above and in the previous chapter *"many discourses of [health and research] practice do not always sit easily with partnership with young people"* (Todd, 2012, p.189). But as the examples above highlight there are some innovative examples which seek to be participatory, inclusive and socially-just through *"a more nuanced approach that looks critically at [the] purpose, consent, method and interpretation"* of young people's participation (Todd, 2012, p.191).. This study sought to explore in more depth how such a critical and reflective approach to participation in practice could inform the embedding of young people's participation.

3.3 Who is heard?

3.3.1 Children and young people's experience of participation

Respecting children and young people is key to embedding participation, but in a report submitted by young people to the UN Committee (CRAE, 2015b) the majority of 840 children and young people who responded to a CRAE survey:

> *"...said that they had not been involved in decisions about their own health care or about the health services in their local area. Only 29% of children [said that] they had had a say in relation to their health care or health services more generally. Of those children who had been involved in decision-making on health care issues:*
>
> - *45% said something had been done differently as a result;*
> - *51% got what they wanted as a result of being involved in the decision-making process;*
> - *62% felt listened to and respected"* (CRAE, 2015b, p.35)

Arguably 'getting what they wanted' is not necessarily a marker of the success or otherwise of participation, but it is clear from this survey that involvement in shared decision-making about individual healthcare or health services more generally is important to children and young people. This is self-selected sample but it nonetheless raises some

interesting issues. It is striking that 71% of respondents to the survey said they had not been involved in decisions, and of the 29% who said they had been involved less than half said something had changed as a result. Echoing the CRAE survey a Care Quality Commission for NHS England found that 43% of 12 to 15 year olds said that they were not fully involved in decisions about their health care and 38% said that a member of staff did not 'completely' tell them what would happen after they left hospital (CQC, 2015).

Children and young people in CRAE's young people-led research reported that they had not felt listened to by medical staff (CRAE, 2015b). Others gave examples of medical staff double checking with adults or ignoring their explanations, with children and young people reporting repeated incidences of not being believed by medical professionals (CRAE, 2015b). Although the associated civil society report (CRAE, 2015a) acknowledges that progress had been made in giving children and young people a voice in national and local strategic health decisions, a key barrier is *"England's health complaints and advocacy system, which is complex, inadequately resourced and fragmented"* (CRAE, 2015a, p.8). Furthermore the CRAE research found that participation of children and young people in English health services is neither universal or inclusive, with considerable regional variations and a lack of a strategic, coordinated approach between health and policy areas such as welfare, poverty and criminal justice, which had a potential impact on childhood health inequalities (CRAE, 2015a).

In addition to the piecemeal approach to participation there are disparities in the characteristics of children and young people likely to participate, the types of decisions they are involved in making, and the extent to which this participation is meaningful and effective (Cockburn, 2005; Davey, 2010; Percy-Smith, 2010). The mechanisms of formal participation may also privilege the already privileged (Crowley, 2015), as discussed in 2.2.2. This is reflected in uncertainty about *'how to involve a diversity of patients and the public, rather than a few selected individuals'* in healthcare (Ocloo and Matthews, 2016, p.2). The CRAE survey found that young children (pre-secondary school age), disabled children and young people and children and young people in care, among other 'less frequently heard' groups, were still not routinely or systematically involved in individual or strategic decision-making in health services (CRAE, 2015a and b).

There has been relatively little discussion about how best to involve a wider range of children and young people in health research, including those who are less frequently heard (Brady, 2015). For example in a 'statement of aspiration' on *"improving research by involving children and young people"* published by the National Institute of Health Research (NIHR, 2016) the only model of participation discussed is the young people's

advisory group (YPAG). But 'children and young people' are far from a homogenous group; age and other aspects of social background such as race and ethnicity, disability, social class, family background and use of services:

> *"intersect as aspects of who [young people] are, their social position, and what researchers need to consider' in designing research approaches appropriate to the young people they wish to involve"* (Clavering and McLaughlin, 2010, p.604).

The voices of children and young people who are less frequently heard, are often absent from the literature on children and young people's participation in research (Richards, Clark and Boggis, 2015). For example users of mental health services (Mawn *et al.*, 2015) and looked after children and young people (Powell and Smith, 2009) are less likely to be involved in research, as are the young people with experience of substance misuse services we sought to involve in my second case study. When *"doing participatory research with children and young people at the margins of society"* it can be helpful to take a flexible approach *"creating pockets of participation"* (Franks, 2011 p.15), in which the appropriate level of involvement is determined by the circumstances of the children and young people involved. As well as having a right to have a say in matters which affect them children and young people also have the right to choose whether or not to participate. Individuals who may be under significant stress might see limited personal benefit to being involved as a research collaborator. It can be particularly difficult to involve children and young people in research on sensitive topics, such as those which are private, stressful *or "potentially expose stigmatising or incriminating information"* (Lee, 1993, cited in Powell and Smith, 2009, p.128), issues which this study sought to address.

3.3.2 The role of gatekeepers

The participation of children and young people often includes adults, either parents and carers or professionals, who may as act as 'gatekeepers' and both enable and potentially constrain children and young people's participation (Cree, Kay, and Tisdall, 2002; Hood, Kelley and Berry, 1996). Researchers' access to children and young people is often tightly controlled (Alderson, 2001; Sinclair, 2004) and generally requires the permission of adults (Hood, Kelley and Berry, 1996). Children and young people can be powerless in this process and reliant on significant adults to decide what information they should be given and whether they can participate (Powell and Smith, 2009). Although gatekeepers often play an important role in safeguarding the interests of children and young people *"they can also act to exert power over young people to prevent their voices being heard"* (Moules, 2005, p.142). In a review of the literature on children and young people's participation in health services Coyne (2008) found that healthcare professionals and parents play a significant role in whether and how children and young people's efforts to participate are facilitated

and supported in clinical settings, and that many have reservations or concerns about children and young people's active involvement.

3.4 Conclusions

As in the academic literature discussed in the previous chapter children and young people's participation is a popular concept, which is increasingly reflected in legislation, guidance, regulation and policy in relation to health services and research. But despite the stated importance of children and young people's participation in legislation and policy their views are still not consistently sought or acknowledged within health settings, especially at a local level. Implementation of children and young people's rights in health services in practice is patchy and often limited to individual participation rather than collaboration in the commissioning, delivery or evaluation of health services. There is also a lack of evidence about how children's rights and participation guidance are implemented in practice, and whether this necessarily always leads to improved outcomes for children and young people, policy-making, service delivery or research. Participation faces many challenges in the face of the realities of clinical and research practice: the values and ideologies of professionals, organisational systems and processes which may be odds with the priorities and concerns of children and young people and adult gatekeepers who can both enable and potentially constrain children and young people's participation. There are also disparities in the characteristics of children and young people likely to participate in health services and research, the types of decisions they are involved in making, and the extent to which this participation is meaningful and effective. Where there are examples of more participatory and inclusive practice these appear to engage more critically and in a more nuanced and reflective way with the realities of children's rights in practice, seeking to embed participation collaboratively in organisational structures and cultures rather imposing it from the top down. All these issues again highlight potential gaps between the rhetoric of participation and the reality, which this study seeks to address. The next chapter discusses the research approach with which I sought to address these issues, based on the theoretical framework outlined in 2.6.

4. Research approach

This chapter outlines the study design, my role, ethical issues and how I approached the analysis of the learning and material which emerged during this study.

The chapter which follows outlines the process of critical inquiry which emerged from this approach and took place alongside the review of the literature discussed in Chapters 2 and 3. The research process in the two case studies is then detailed in Chapters 6 and 7.

4.1 A participatory paradigm

This study sought to understand how organisational culture, systems and practice support or create barriers to young people's participation, and to locate this within a framework of participatory, rights-based research (Boyden and Ennew, 1997; Beazley and Ennew, 2006). My research approach is underpinned by a theoretical framework, outlined in 2.5, through which I sought to engage in practical and collaborative inquiry within a participatory paradigm (Heron and Reason, 1997). I was interested in action research as an approach which would enable me to *"replace methodological individualism with a collaborative [social constructionist] epistemology"* (Gergen and Gergen, 2008, p.159). Although action research is a field in which there is considerable fragmentation and debate about terminology (McNiff, 2013) it is generally understood to be a process of reflexive inquiry:

> *"...that is done by or with insiders to an organisation or community, but never to or on them. It is a reflective process...[which] is oriented to some action or cycle of actions that organisational or community members...are taking, or wish to take, to address a particular problematic situation".* (Herr and Anderson, 2015, pp.3-4)

There are debates about whether action research is *"a separate epistemology or merely a type of applied social research"* (Herr and Anderson, 2015, p.52). Action research is linked to standpoint epistemologies: *"...ways of knowing and understanding implicit in the experience of particular social groups"* and therefore privileges lived experience (Stringer, 1999, p.205):

> *... "the usual distinction between ontology (the nature of reality) and epistemology (how one comes to know that reality) collapses: Inquirers do not discover knowledge by watching nature do its thing from behind a thick one-way mirror; rather it is literally created by the interaction of inquirers with the object (construct) inquired into".* (Stringer, 1999, p.xii)

This suggests that action research is a post-positivist approach within a critical realist framework, and a paradigm rather than a methodology (Poonamallee, 2009). Action research is a way of *"working towards practical outcomes, and also creating new forms of understanding"* (Reason and Bradbury, 2008, p.2), and fitted with my intention to work collaboratively with those involved in children's participation to identify *"not just solutions to the immediate problems but important learning from outcomes both intended and unintended, and a contribution to scientific knowledge and theory"* (Coghlan and Brannick,

2010, p.5). This thesis explores the conceptualisations and understandings underpinning young people's participation, and how these informed practice. Kemmis and McTaggart (2000) describe action research as involving self-reflective cycles of planning a change, acting and observing the process and consequences of that change, reflecting on these processes and consequences and then replanning, acting and observing, reflecting, planning further change and so on. This informed my work with the case studies and the development of my initial ideas in a process of critical inquiry with a wider group of stakeholders *"including policy makers and those 'on the receiving end' of policy"* (Torrance, 2011, p.577). Both the case studies and critical inquiries were rooted in the assumption that theory and practice are intertwined in action research, integrating *"the development of practice with the construction of research knowledge in a cyclical process"* (Noffke and Somekh, 2011, p.94), rather than *"the mere recording of events and formulations of explanations by an uninvolved [traditional, positivist] researcher"* (Stringer, 1999, p.7).

However the uncertainties and competing priorities inherent in doing participative research meant that I needed to remain flexible and responsive:

> *"…no one may mandate in advance that a particular research process will become a fully developed participatory action research project. Participation is a process that must be generated. It begins with participatory intent and continues…within the limits set by the participants and the conditions*". (Greenwood, Whyte and Harkavy, 1993, p.175-176)

The idea of participatory intent appealed to me, given the unpredictable nature of participative research which:

> *"…is research within which there is a social contract, that honours and values the multiple voices and perspectives of those who take part… [it is not an approach] where the adult abdicates from the inquiry, but where adults, children and young people work in partnership with each other".* (Groundwater-Smith, Dockett and Bottrell, 2015, p.22)

Such an approach requires the engagement children and young people *"as active, informed and informing agents"* in order to interrupt the adult-dominated discourses which create barriers to children and young people being *"fully engaged in those social agencies that govern their lives"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.9). By seeking to actively involve young people in the research process I explored the interconnections between their participation in health research and services, and attempted to reflect my subject matter (participation) in order that subject and method were tied together (Thomas, 2002). Taking a participative approach, informed by the action research cycle of plan-act-observe-reflect (Lewin, 1948), enabled me to open up to critical inquiry existing assumptions and practices concerning participation and understand the systemic arrangements required for young people's participation to be embedded effectively. By facilitating collaborative learning and reflection with my case

study stakeholders on the process as well as the outcomes of participation, new insights and possibilities were able to emerge as the research process unfolded.

In this study I adopted a relativist ontological position seeking to understand the case studies as a series of different constructions, rather than external realities independent of participants' beliefs and understanding (Ritchie *et al.* 2014). In action research the aim is not to search an external reality or 'truth' but to investigate the subject of study (in this case participation) in a particular context and in ways which have meaning for those involved (McNiff, 2013). My approach was also informed by the view that the creation of knowledge is subjective and context-specific, and that knowledge is built iteratively (Pawson, and Tilley, 1997). Therefore the focus of this study was on facilitating a process of shared learning about participation in the context of these two specific case studies, with the knowledge which emerged contributing to wider knowledge and theoretical understanding of the processes and dynamics required to embed participation.

The question of how to judge the quality of a study such as this also needs to be addressed. There is considerable debate about what is meant by 'quality' in quality research (e.g Dixon-Woods *et al.* 2004; Ritchie *et al*., 2014), reflected in the various frameworks and criteria for judging qualitative research (e.g. Spencer *et al.*, 2003, Tracy, 2010). There are arguments for and against using explicit assessment criteria to judge the quality of qualitative research, particularly in the application of traditional quantitative positivist criteria around validity, reliability and rigour to the methodological and epistemological pluralism inherent in qualitative research (Braun and Clarke, 2013, Hammersley, 2007). Health research is an area in which qualitative studies have had to overcome more misconceptions that may be usual in other fields (Mays and Pope, 2006), with qualitative research generally judged to be a low priority, and 'lacking practical value' by the most prestigious academic journals (Greenhalgh *et al*. 2016). Some commentators argue that qualitative health research therefore needs to pay particular attention to rigour in design, data collection, interpretation and communication in order to 'hold its own' in a field dominated by quantitative randomised control trials (Dixon-Woods *et al.*, 2004; Mays and Pope, 2006; Seers and Toye, 2012). I have sought in the chapters which follow to demonstrate a rigorous approach and to reflect on the strengths and weaknesses of my research. But I have also been conscious of the participatory values which underpin this study, as outlined in 2.5, as 'non-epistemic' quality criteria *"in terms of 'giving voice' to the marginalised or bringing about practical or political effects of some kind"* (Hammersley, 2007, p.292). This has included consideration of quality criteria for participatory research: Was the research relevant to participants? Was consideration given to the local context when implementing change? Was the relationship between the researcher and

participants adequately considered? Was the study design flexible and responsive? (Hughes, 2008). Groundwater-Smith, Dockett and Botterell (2015) argue that effective participatory research with young people:

> *"…must reflect standards of good quality research…[and in addition be] based on genuine respect for participants, with regard to their knowledge and expertise…[and] underpinned by commitments to reporting and dissemination that aim to make a positive difference"* (Groundwater-Smith, Dockett and Botterell, 2015, p.67).

So in addition to considering wider issues of research quality this study also draws on standards relevant to the participatory, rights-based framework within which my research was located.

4.2 The researcher as actor

In addition to working collaboratively and generating shared learning, it was important to locate myself as an actor in the research process, and reflect on the roles I played. Rather than seeing knowledge as "*a free-standing unit, to be found 'out there' and separate from the people who create it"*, using a participatory research approach enabled me and those with whom I was collaborating to see knowledge as something generated from our experience, *"a living process"* which was in a constant state of development (McNiff, 2013, pp.28-29). Throughout the research process I sought to critically reflect on the understandings, values, preconceptions and actions that I brought to this study, and how I located myself in facilitating co-learning, participation and organisational transformation. A PhD is about deepening academic knowledge, and I chose to undertake this study because of a longstanding interest in this area (see 1.3) and the opportunity provided to deepen my knowledge and understanding. But this study also had a practical focus, and I was keen that it should also contribute directly to the embedding of young people's participation in health services and research. I chose to use participatory research methods in order to facilitate both my own research practice and the development and delivery of young people's participation in health services and research. This thesis is a key output from this study but, in order to influence policy and practice, the research also needed to be relevant to the commissioners and providers of services and to young people themselves. This study therefore needed to have practical as well as theoretical application and encourage reflection and action through collaboration during the research process. By working with the two case studies this study developed shared learning on how participation can best be embedded in health services and research and support tangible changes in practice.

There are inherent tensions between taking a participatory research approach and the requirements of doctoral research (Herr and Anderson, 2015), not least the need to demonstrate my ownership of the resulting work, as well as that the timing of the various

phases was led by the overarching doctoral timetable rather than the requirements of the case study sites. There are epistemological challenges for action research in academic researchers being seen as people qualified to *"generate theory out of their expert knowledge"* with practitioners relegated to the role of implementing these theories (McNiff, 2013, p.4):

> "*It is not so much a matter of who does the research in terms of gathering and interpreting data as of who is seen as competent and authorised to generate the theory, and who makes decisions about these things" (*McNiff, 2013, p.4-5*).*

I became increasingly aware of the issue of ownership as the study progressed. On the one hand the impetus and timing for this study came from the University of the West of England (UWE), as this study was initiated through an advertised studentship for which I successfully applied. On the other hand I wanted as far as possible to let the direction of travel emerge through collaboration with stakeholders in my two case studies, and it needed to be a process which had meaning and value for them as well as academically.

In order to take an integrative and action research-based approach, and critically reflect on both the research process and the integrity of that process through*"rigorous self-reflexivity"* (Poonamallee, 2009), I used a reflective diary to include first person (inquiring into *my "basic assumptions, desires, intentions and philosophy of life… behaviour, ways of relating and action in the world"*), second person *("ability to inquire into and work with others on issues of mutual concern"*) and third person reflections (learning on how participation is embedded) (Coghlan and Brannick, 2010, p.6) that arose during the research process. I was operating on at least three levels during the two years I was actively working with the case studies: as a PhD student, as an external facilitator of an action inquiry process in one case study, and as a co-applicant and participant researcher in the other. It was important to think through my multiple roles during this study (Herr and Anderson, 2015) by reflecting on how my presence might be affecting what happened.

4.3 Summary of the research process

This study was broadly divided into four phases, although these phases were iterative and overlapping to varying degrees:

Phase one (January 2013 – February 2015): My main focus at this time was the literature review which informed Chapters 2 and 3 and the critical inquiry process discussed in the next chapter. But both of these activities continued to a lesser extent throughout this study, as I continued to search for relevant academic and grey literature and to engage with policymakers and practitioners at events and on social media.

Phase two (September 2013 – July 2014): Case study fieldwork. Although collaborative learning took place throughout this study this was the period when the majority of my time was spent working with the two case studies, facilitating the shared learning and activity which informs my findings (Chapters 8 to 11).

Phase three (September 2014 – March 2015): Collaborative analysis: further meetings and interviews with case study participants as part of a process of collaborative analysis. This included discussion and reflection on emerging findings from my initial analysis and the production of associated outputs (e.g. Appendices 3 , 8, 9, 11 and 12).

Phase four: Analysis and writing up.

4.4 Taking a case study approach

4.4.1 Rationale for using case studies

Case study research involves the detailed and intensive study of phenomena studied in the context of one or more case studies, using of multiple data collection methods and from multiplicity of perspectives or a number of specific contexts (Ritchie *et al.,* 2014). Taking a case study approach appeared from the outset to be a useful and pragmatic methodological approach to investigate the embedding of young people's participation in health services and research. Case studies are *"an empirical inquiry about a contemporary phenomenon…set within its real world context"* (Yin, 2009, p.18) which focus *"on understanding the dynamics present within single settings"* (Eisenhardt, 1989, p.534). Using case studies enabled me to focus on in-depth study and the social construction of cases (Chadderton and Torrance, 2011), in this case of the embedding of young people's participation in health services and research:

> *"All case study research starts from…the desire to derive a(n) (up-)close or otherwise in-depth understanding of a single or small number of 'cases' set in their real-world contexts…hopefully resulting in new learning about real-world behaviour and its meaning"* (Yin, 2012, p.4)

This can be particularly useful when no single perspective can provide a full account or explanation of the research issue, and where understanding needs to be holistic, comprehensive and contextualised (Ritchie *et al.*, 2014). This approach enabled me to construct the case studies as the sites for encounters and social action related to young people's participation from multiple perspectives, exploring the meanings brought by different actors, and using multiple methods and data to explore and interrogate instances in action (Chadderton and Torrance, 2011):

> *"case study assumes that 'social reality' is created through social interaction, albeit situated in particular contexts and histories, and seeks to identify and describe before trying to analyse and theorise"* (Chadderton and Torrance, 2011, p.53).

Action research case studies are located within an applied research and evaluation case study tradition which focuses on improving decision-making and practice, but has the emphasis on *"planned development in situ"* (Chadderton and Torrance, 2011, p.53). As discussed above I used a participatory action research-informed approach to work with two case studies, in order to explore collaboratively the realities of trying to embed young people's participation in health services and research.

4.4.2 Generalisability and learning

One common criticism of case study methodology has been the focus on understanding the case rather than generalizing to the population at large (Eisenhardt, 1989):

> *"...analytic generalisations [in case study research] depend on using a study's theoretical framework to establish a logic that might be applicable to other situations."* (Yin, 2012, p.19).

But the depth and richness of the learning which can emerge from case studies means that research findings can have more general relevance or interest and illuminate general issues (Chadderton and Torrance, 2011). There are also questions about what one is generalising too as *"case studies tend to generalise to other situations"* rather than to populations (Yin, 2012, p.19). This was certainly the case with this study as, although based on specific examples, there are many points of learning which are generalisable to other health services and research studies seeking to embed children and young people's participation. Indeed the framework for embedding participation presented in Chapter 12 seeks to extrapolate and synthesize the key points of learning about what it means to embed young people's participation in health services and research.

However 'generalisability' is in itself a positivist construct, for example when it is assumed that the practice-driven knowledge which is generated through action research does not have the same validity as theory-driven knowledge beyond the practice setting (Herr and Anderson, 2015). But in action research 'objectivity' and 'truth' are not absolute truths but relative positions which are collectively agreed (Ospina *et al.*, 2008). Research has credibility when *"the truth and [co-created] knowledge of the community is both privileged and communicated"* above researchers' interpretations and 'generalisable' knowledge (Grant, Nelson and Mitchell, 2008, p.598). Herr and Anderson (2015) suggest that there are potential challenges inherent in undertaking a participatory PhD both as a researcher (see 4.2 above) and, in relation to generalisability: in demonstrating the how the research has led to the production of new knowledge. These challenges can be addressed through a combination of dialogic validity (participating in critical and reflective dialogue with other action researchers) and process validity *("problems are framed and solved in a manner which permits ongoing learning of the individual or system"*) ((Herr and Anderson, 2015,

p.68). I addressed the former through discussions with my supervisors, joining an action research group within my faculty and attending external workshops for action researchers; the latter I addressed through analysis of emerging learning with case study participants and writing up of the findings in the chapters which follow.

4.4.3 Selecting and defining the case studies

There were empirical, verifiable, ethical and pragmatic reasons for this study taking place in the two case studies outlined below. As outlined in Chapters 2 and 3 children and young people's participation in health services and research is extremely variable, with few published studies which have critically reflected on the practice of participation in either field, and even more limited shared learning between the two fields. I therefore sought case studies which appeared to combine innovative practice and a commitment to participation, as well as being sympathetic to the participatory ethos of the study and willing to commit the necessary time and resources. My selection was theoretical in the sense of:

> *"Selecting groups or categories to study on the basis of their relevance to your research questions, your theoretical position..[and] the explanation or account you are developing. It is concerned with constructing a sample...[which] helps to develop and test your theory or explanation".* (Silverman, 2000, p.105)

Ritchie *et al.* (2014) describe 'heterogenous' and 'extreme case' sampling, both of which have relevance to this study, the former are *"...a deliberate strategy to include cases that vary widely from each other" in* order to identify central themes and the latter where *"cases are chosen because they are unusual or special and therefore potentially very enlightening"* (p.114). Selection of case studies is also generally structured around contexts rather than a series of individual participants, with the researcher considering the balance between breadth and depth within the case study (Ritchie *et al.*, 2014). But there are challenges in where one draws the boundaries of a case study (Chadderton and Torrance, 2011). A case is not necessarily a physical location or organisation and *"case studies need to pay attention to the social and historical context of action as well as the action itself"* (Chadderton and Torrance, 2011, p.54). Ritchie *et al.* (2014) propose that the design of case study research can be based on a process, an organisational context or a geographic area, the unifying factor being that the research is structured around a context, institution or location rather than a series of individual participants. But (Yin, 2012) points out that the boundary between a case and its contextual conditions can be blurred when the case is the main unit of analysis, but there are also nested units or subcases within the main unit. This was certainly the case in this study, when there were various groups within each case study with very different perspectives (most obviously adults and young people, but also professionals, parents and other sub-groups such as commissioners). Yin (2012) further

distinguishes between *explanatory case studies* which seek to explain how and why a series of events occurred and *descriptive case studies* which can provide:

> *"…revealing insights into the social world of a particular case - e.g. instances of exceedingly successful (exemplary cases) or unique situations as well as revelatory or typical (ordinary) cases."* Yin. 2012, p.49)

Drawing on all of this my design was an embedded multiple case study (Yin, 2012) structured around descriptive, organisational cases; both of which were selected because they appeared to be in some way unique and possibly exemplary. The first (discussed further in Chapter 6) was a children's community health service run as a partnership between an NHS Trust and a voluntary sector organisation, which was attempting to put into practice many of the ideas I wanted to explore about what it meant to embed participation. The second (discussed further in Chapter 7) was a randomised controlled feasibility trial in which I was a co-applicant, in which we were seeking to involve young people with experience of substance misuse services. Purposive or criterion-based sampling in case study research is based on identifying cases:

> *"…which have particular features or characteristics which will enable detailed exploration and understanding of the themes and [research] questions."* (Ritchie *et al*, 2014, p.113).

However sampling - as generalisability above - is also a positivist construct (Alvesson and Skoldberg, 2009) which does not necessarily sit well with participatory research. While it was important to consider carefully my choice of case studies, using action research was an effective way to identify *"personal, social and political values"* (in this case around young people's participation) and ask *"what these values might look like in practice"* (how rhetoric became reality) (McNiff, 2013, p.92). So while my case studies were not selected through formal purposive sampling I chose them because they both provided unique opportunities for experiential learning about existing assumptions and practices concerning young people's participation in health services and research.

4.5 The case studies

My first case study, the Community Children's Health Partnership (CCHP), was an NHS Trust working with a voluntary sector organisation to support children and young people's participation in the development and delivery of the partnership. The second, the Youth Social Behaviour and Network Therapy study (Y-SBNT), focused on young people's involvement in an adaptation and feasibility study of an intervention for young people who misuse alcohol and drugs. In each case study adult professionals and young people were actively involved in generating learning as co-enquirers, as discussed below and in Chapters 6 and 7. The methodology was therefore subject to agreement with participants in each setting, but involved my facilitating participatory inquiry with stakeholders in each

case study through co-learning, inquiry, participation and organisational transformation (Greenwood and Levin, 2007) in a process which aimed to have both practical and theoretical outcomes (Stringer, 1999). Key areas of exploration included: the systems and structures required to support participation, the role of organisational cultures and shared values, the spaces in which dialogue and learning took place, the quality of relationships between young people and adults, the extent to which young people were involved in different phases of the decision-making cycle, and if and how participation brought about tangible outcomes that had value for young people and services. These areas emerged from my initial reading of the literature alongside the critical inquiry process discussed in Chapter 5, and were further developed during the processes of co-inquiry outlined in Chapters 6 and 7.

4.5.1 Participants

In both case studies there was a core group of adults and young people involved throughout the process and others who moved in and out of the inquiry depending on availability, interests and what was required at different stages. Who was involved and when was determined in consultation with key stakeholders in each case study, including young people, as well as practical considerations such as availability and interest.

Table 1: Summary of case study participants

Case Study one: CCHP	**Case Study Two: Y-SBNT study**
NHS Trust and voluntary sector organisation managers and commissioners (active partners) Staff in a range of services across the Health Partnership (active partners) Young people involved in CCHP participation activity (active partners) CCHP management groups (focus group participants) Members of a learning disability service's parents group (focus group participants) Members of the Clinical Commissioning Group (focus group participants) Organisations collaborating with the Health Partnership and other stakeholders (focus group and interview participants)	Members of the Trial Management Group (active partners) Members of the Trial Steering Committee (focus group participants) Young people involved in the study as young advisors (active partners) Organisations supporting the engagement of young people in the study (at meetings and as interview participants)

4.5.2 Capturing learning from the case studies

"Case studies typically combine data collection methods such as archives, interviews, questionnaires and observations" (Eisenhardt, 1989, p.534). Similarly in action research *"data [can] take the form of field notes, observations, questionnaires, reports, diaries and logs"* (McNiff, 2013, p.107). Learning from the CCHP case study was principally generated through a series of workshops with staff and young people, detailed in 6.3-6.5, as well as semi-structured focus groups as outlined above. A selection of workshop and focus group materials are included in Appendix 5. Workshops included activities such as photovoice (Wang and Burris, 1997) and other creative methods (Shaw, Brady and Davey, 2011). Such creative methods were also important as a researcher:

> *"…seeking genuine engagement with children in research… [as] innovative [research] methods [were used] with the intent of emphasizing children's competence, agency and participation rights".* (Dockett, Einarsdottir and Perry, 2011, p.77)

I produced notes or newsletters after each workshop, where possible in collaboration with participants, which were circulated to all those involved (e.g. Appendix 6). Documents from the workshops formed part of the body of material which informed my analysis along with recordings and transcripts of group discussions in workshops and focus group discussions, session plans and materials produced for workshops, meetings notes, emails and my own journal notes and reflections.

Learning from the Y-SBNT case study emerged rather differently, as the changing process outlined in Chapter 7 meant that learning was generated on a more ad hoc and less collaborative basis than in the CCHP. Material included analysis of transcripts of focus groups with the study's trial management group (TMG) and steering committee (TSC), transcripts of phone and face to face meetings with two young advisors about their involvement in the study, meeting notes of discussions about young people's involvement at TMG and TSC meetings; notes and transcribed conversations from young advisor meetings, and newsletters and other materials developed for and with young people (Appendices 10 and 11). I also drew on my own notes on meetings and discussions with others involved in recruiting and supporting young people's involvement in this study, my research journal, and the study proposal and protocol (Watson *et al.,* 2015). Focus group topic guides are in Appendix 9 as well as some example materials and notes from young advisors meetings. These meetings, as with the CCHP workshops, included a range of creative and participatory methods, including using a river of experience approach (Percy-Smith, 2011) to map young people's participation in the study. A full list of all material used in my analysis is included in Appendix 14, including when activities were undertaken and with whom and summarising material included in my analysis.

4.6 Other sources of learning

4.6.1 Journal

My research journal (see 4.2 above) was kept mainly electronically, using Evernote software, as I found this helpful as a way of organising my thoughts and also being able to tag entries for retrieval later on so I could search by theme or keyword as well as date.

4.6.2 Social media

I set up a blog linked to this study in July 2013, originally to support and promote a workshop I planned as part of the critical inquiries discussed in the next chapter. I found this useful both as a way of promoting and creating a record of the event, including posts with the presentations and reports on the day (including one by a young person who attended) (Brady, 2013). Since then I used the blog intermittently to record emerging thoughts and share conference presentations. The latter enabled me to reflect in more depth on the issues touched on in various conference and workshop presentations over the course of this study, capturing my thinking at the time and also enabling me to use the blog as a platform through which to engage stakeholders and give young people a voice in this study (e.g Hathway, 2014). As with any other publications or outputs from research blog posts did not include any confidential information relating to, or identifying participants (Jones 2011b). I had hoped that blog would be a way to engage people in dialogue as this study progressed, and some of my blog posts were shared and received positive feedback, But in practice, while it was a useful way of inviting people from a wider sphere to engage in the inquiry and get positive feedback in the form of posts being shared of or 'liked', there was relatively little interaction.

The workshop mentioned above prompted me to set up a Twitter account and create a 'hashtag' for the workshop. As this study was both about participation and seeking to be participative I found Twitter an interesting way of creating a collaborative narrative of the event which I was able to capture and share through Storify (Brady, 2013). Twitter also helped me engage with young people, practitioners, policy-makers, academics and others with an interest in my research topic. As this study was grounded in policy and practice, it was helpful for keeping engaged with the 'real world' context for this study beyond my work with the case studies. This did not form part of the material for analysis, but rather enabled me to develop networks, become aware of resources and sources of information, and share ideas with people in a public forum as a stimulus to my own reflective inquiry. My Twitter profile made it clear that I was tweeting about my research topic. In my ethics application I said that if I was going to discuss material from Twitter I would follow guidance that *"if consent has not been obtained…researchers must ensure that they report*

only depersonalised data from social media sources" (ESOMAR, 2011, p.7). However in the event this proved not to be an issue as no material from social media activity is quoted in this thesis other than my own blog posts and others for which I have obtained consent.

As I was based off campus as well as being in a Faculty where other postgraduate researchers were engaged in clinical and quantitative research, Twitter was also helpful in building a virtual community of others with related research interests and identifying new literature. Alongside this study I was also involved in an NIHR INVOLVE steering group for the development of guidance on using social media for public involvement in research (INVOLVE, 2014a), which informed my attempts to use my blog and Twitter to engage young people and families in this study. But the use of blogs, Twitter and other social media in academic practice generally, and in participative research in particular, are areas that merit further exploration (NSMNSS, 2016).

4.7 Ethical challenges

Although some of the CCHP work took place in NHS settings the National Research Ethics Service deemed that, by their definitions, this study was characterised as service evaluation and development and therefore was not considered to require review by an NHS Research Ethics Committee (REC). The CCHP asked me to submit an application to their Clinical Effectiveness committee, in lieu of submission to the Trust REC, and this application was approved. An ethics application was submitted to the UWE Health and Life Sciebces Faculty Research Ethics Committee on 10th June 2013, and approved subject to minor revisions, including a request for clarification on how issues of confidentiality and anonymity would be addressed in the case of blogs and social media (Appendix 4).

4.7.1 Concerns about vulnerability

Adults and young people in the two case studies were actively involved as co-enquirers and the methods and tools used were therefore subject to their agreement, which complicated the idea of obtaining prior ethical approval. Although the risk of harm to participants in the study was low I needed to consider the fact that I would be working with young people who could be defined as particularly vulnerable. My first case study included young people in care and young people using mental health services, and my second case study involved young people who had received treatment in drug and alcohol services. In my ethics application I made the point that, although potentially difficult, it was important to involve these young people because it was a participatory study about young people's participation and would therefore be fundamentally flawed if young people were not active participants in the process. It was also important to consider the

participation of young people who were considered to be vulnerable, and therefore less frequently heard. As part of my responsibility to ensure the safety and welfare of anyone participating in this study, I had a duty to avoid or minimise any harm due to the research process itself. The ethical issues raised during the study are discussed further below, but the focus in ethical approval processes on protecting the vulnerable suggest tensions with participation rights which echo those discussed in Chapter 3. While there are many standard ethical considerations associated with researching children and young people:

> *"…[there are] tensions between researchers who seek to empower children to participate and hear their opinions and those who seek to regulate studies to protect children and their right to privacy"* (Richards, Clark and Boggis, 2015, p.3).

For example the UWE ethical review form asked whether research participants would be from one or more vulnerable groups, one of which was 'children under 18'. The form then stated *"If any of the above applies, please justify their inclusion in this research"***.** The fact that the ethics form required me to justify the inclusion of children under 18, rather than being concerned about their exclusion, suggests that the focus of the ethical approval process was on protecting those deemed to be vulnerable, of seeing children and young people as *"objects of concern"* who need to be protected rather than *"persons with a voice"* (Hallet and Prout, 2003, p.1). In this study and previously I have found that it is much more helpful to regard children's rights to privacy and protection and their right to active participation in research as *"complimentary rather than oppositional"* (Richards, Clark and Boggis, 2015, p.3). I therefore addressed issues of informed consent, access and anonymity as outlined below while retaining a focus on enabling young people's active participation in the research process.

4.7.2 Consent

Once potential participants had been identified they were provided with written information in advance (Appendix 2). The purpose of the study and what taking part would entail was explained to potential participants verbally as well as in writing. Signed consent was obtained for all adults and young people taking part in the generation of collaborative learning, interviews and focus groups. When working with young people I was particularly alert to any signs of discomfort, and if possible tried to provide a safe space nearby (e.g. a member of staff on standby in a nearby room) if a young person wished to withdraw at any point. If further support was needed for any reason young people involved in the CCHP case study had ongoing support from participation staff, and my colleagues and I provided support to young people involved in the Y-SBNT study as young advisors. If a participant decided they no longer wished to be involved, I respected this while also offering them the option of taking a break and re-engaging at some point in

the future. How recruitment and consent played out in practice are discussed further in Chapters 6 and 7.

Signed consent was sought from partners and participants and, in the case of young people under 18, also from their parent or guardian. If there had been exceptional reasons for doing otherwise (e.g. a child as estranged from their parents), I had agreed with the UWE ethics committee that I would seek expert advice before making a decision, for example seeking consent from an adult acting in loco parentis. But, as discussed in 4.7.1 the issue of consent suggests tensions for ethical research practice between children's rights to privacy and protection and their right to active participation. There is a risk, particularly for children and young people from groups deemed to be particularly vulnerable, that:

> *"…construct[ing] children and young people's 'consent' as somehow lesser than adults is the privileging of particular voices over others"* (Richards, Clark and Boggis, 2015, p.153).

The result of ethical review and formal consent processes can be to create a long 'chain of consent', with children and young people often the last to be consulted, resulting in some children and young people *"being more readily accessed and thus more readily heard"* (Richards, Clark and Boggis, p.153). For example one 15 year old involved in the Y-SBNT study who was estranged from her family and living independently. The young person was keen to take part and requiring parental consent would have prevented her from doing so. This accords with guidance that consent may be waived *"if seeking parental consent would potentially breach a child's right to confidentiality"* (Shaw, Brady and Davey, 2011, p.27), and her participation was agreed on this basis with project worker supporting the young person's participation and by the TMG. But there is a need for further discussion about the process of ethical review and the implications for children and young people's participation in research in terms of both participation rights and assumptions of competence (e.g. Cockburn, 2005; NSPCC, 2016).

Ethical research practice is more than a signed form and agreement from an ethics committee, particularly in a participatory study which entailed a commitment over time. Written consent was obtained for the duration of their involvement for all adults as well as young people in the first of my case studies (the health provider), to avoid the need to obtain consent for every meeting or other activity that they were involved in. However this consent was reaffirmed regularly (though not necessarily formally) throughout this study. The participatory nature of action research is based on principles of shared decision making, wherein an environment is created for participants to be proactive in shaping the research and therefore their participation in it. As the study developed, and offered a range of new or different opportunities for partners and stakeholders to become involved, I

sought to establish rather than assume consent for these changes on an ongoing basis. If partners and stakeholders decided they no longer wish to be involved, I respected this whilst offering them the option of taking a break and re-engaging at some point in the future. I also regularly reviewed consent and tried to make it clear to people that they are free to opt out of involvement in this study at any time.

In the Y-SBNT study issues arose during the course of the study, as discussions at the start of the study on recruitment and consent had initially assumed that the young people who would be involved as young advisors would be the principle sources of learning for this study. Full written consent was therefore obtained from all young people involved during the course of this study. As the research progressed and changed however, questions arose about whether and when written consent is needed from TMG members, and this is discussed further in 7.5.3.

4.7.3 Selective anonymity

While the requirements of confidentiality and anonymity can seem straightforward the reality can be more complex (Braun and Clarke, 2013). Of particular relevance to participatory research is the fact that *"anonymity can be protective of participants, but it can also remove their voice and might conflict with social justice goals"* (Braun and Clarke, 2013, p.63). There are power issues inherent in my 'taking the credit' for work undertaken collaboratively as part of this study, which need to be balanced with the need to protect participants. So in consultation with my supervisors I agreed with case study participants that, although individual contributors would be anonymised the case studies themselves would be named. This was partly to acknowledge the contributions of the organisations involved, but also because the key features of both case studies also make them fairly easy to identify. Prior to submission I sent copies of draft case study and findings chapters to the CCHP participation manager and members of the Y-SBNT TMG and TSC to check for points of accuracy and confirm that they were happy with both how I had used their material in this thesis and the level of anonymity. No objections were raised and the CCHP participation manager and Y-SBNT principal investigator confirmed their support for my decision to name the case studies.

Towards the end of my work with the CCHP the organisation wanted to use the learning which had emerged and promote their involvement in this study. We therefore agreed a further consent process in which people who had ongoing involvement in this study were asked to sign a consent form to say that they understood that the organisation would be named and that, although any direct quotations would be anonymous, they could choose whether or not they wanted to be credited as a contributor in outputs related to this study.

Those who chose to be named would be and others would be included as '…and other contributors'. This echoes the idea of having two forms of consent for action research: *"blanket consent that allows for ongoing inquiry into regular practice…[and] a second one explicitly seeking consent for eventual publication"* (Herr and Anderson, 2015, p.156). I also followed this in quoting from a blog post written by one of the young people with whom I had worked at CCHP. The post is the public domain (Hathway, 2014) but I nonetheless needed to consider both the young person's right to be credited for her contribution and her right to anonymity. I discussed the issue with her and offered her the option of the blog being anonymised or deleted so that it would also be anonymous in this thesis, or crediting and referencing her material. Her response:

> *"I am more than happy for it [the blog post] not to be anonymous. I am just kind of working out how to merge the identity of service user and professional, no problems so far but it has required some mindful navigation"* (Email, 12/5/16).

I have therefore credited her for the blog post, but this does raise some interesting issues about children's rights to be credited for their contributions and the potential risks of doing so, and issue which also came up in the Y-SBNT study and is discussed in Chapter 11.

4.8 Analysis

4.8.1 Analysis approach

In action research one would expect to see improved learning (McNiff, 2013). I therefore documented emerging learning on understandings and the practice of participation, as well as reflecting on *"what, overall, was learned from the action research process, and how it might inform the larger research conversation"* (Herr and Anderson, 2015, p.91). But the action and participative research literature is often fairly vague on analysis methods:

> *"…it is likely that action researchers will use some data-analysis procedures common to qualitative inquiry."* (Herr and Anderson, 2015, p.91).
>
> *"Interpreting the data means making sense of what you find, using your chosen categories of analysis…in action research, these categories are related to our values".* (McNiff, 2013, p.112)

Narrative and discourse analysis focus on the ways in which narratives and stories are constructed (Ritchie *et al.*2014) but I was interested as much in the process by which knowledge was created in the two case studies (see 4.1), so was or was not done as much as what was or was not said. In order to make sense of the material outlined in 4.5.3 above I therefore used a thematic analysis approach to discover, interpret and report on themes and patterns of meaning relating to my research questions (Braun and Clarke, 2013; Ritchie *et al.* 2014). Case studies can be used to provide description, test or generate theory (Eisenhardt, 1989) and extend or challenge existing theoretical perspectives (Yin, 2012). This study focused particularly on extending and challenging existing theoretical

perspectives on what it means to embed young people's participation in health services and research. The form of thematic analysis which underpinned my analysis was inductive in that it aimed *"to generate an analysis from the bottom up"* but was *"shaped to some extent by [my]…standpoint, disciplinary knowledge and epistemology"* (Braun and Clarke, 2013, p.175). However I found that, while helpful as a broad approach, thematic analysis is a method which has emerged from psychology and focuses on the analysis of transcriptions of individual interviews and focus groups rather than case studies, participatory and action research. It did not address how to deal with the volume and variety of material generated by a study such as this. I therefore turned to Eisenhardt (1989)'s paper on building theory from case study research. Although positivist in approach in that she talks about 'construct validation' and 'hypothesis testing', I found that the process she outlined worked well with an inductive thematic analysis approach and the epistemology and methodology outlined earlier in this chapter. It is also particularly appropriate for research areas *"for which existing theory seems inadequate…or when a fresh perspective is needed"* (Eisenhardt, 1989, p.549), the reasons I had chosen to adopt an inductive approach when first considering thematic analysis.

4.8.2 The process of thematic analysis

The analysis plan outlined in Table 2 below summarises how I applied the approach of inductive theory-building theory to my analysis:

Table 2: Summary of analysis process

Stage	Activity
1	Identified and organised all material for analysis
2	Developed initial thematic maps
3	Scanned and wrote familiarisation notes on individual items of transcribed material, doing preliminary coding linked to initial thematic maps
4	Went back through material using the thematic analysis approach to build up codes and themes, and revised thematic maps accordingly
5	Confirmed themes within-case and then searched for cross-case patterns
6	Discussed emerging findings with case study participants and my supervisors
7	Refined the definition of relevant constructs and assessed the evidence for these constructs within and across cases
8	Verified that the emergent relationships between constructs fitted the evidence in each case study
9	Mapped out emerging theory and constructs with reference to relevant literature, refining and reviewing my conceptual and theoretical framework
10	Brought in non-transcribed material including documents and other materials generated during the process
11	Developed the final coding frame and thematic maps in NVivo in light of 9 and 10 above, which informed the analysis which underpins Chapters 8 to 11.

The first stage was to identify all the material I thought I would use in my analysis, including transcripts, meeting notes, project documents and other material summarised in Appendix 14. Transcribed and other written material such as meeting notes was imported into NVivo in a format suitable for coding. Photographs and other secondary material were also imported and linked to coded documents so that, where possible, I could link transcriptions of discussions about particular documents or creative activities to the items being discussed. Once data was imported and ready for analysis I then developed initial thematic maps structured around my research questions, mapping out key themes and issues based on my review of the literature (Chapters 2 and 3), learning from the critical inquiries (Chapter 5) and my initial reflections (via my research journal and notes). In keeping with Eisenhardt's (1989) approach of building theory from case study research I hoped *"a priori specification of [broad] constructs"* would provide *"a firmer empirical grounding for the emergent theory"* as my analysis progressed (p.536). The first three figures in Appendix 15 are the thematic maps which emerged from this process considering, in turn: how participation was conceptualised and how this related to understandings of childhood and children's rights (p.305), how organisational culture, structure, practice and review informed the reality of participation in practice, and how this related to young people's own ideas and experiences (p.306), and finally the gaps, barriers and challenges to embedding participation in practice (p.307).

What became immediately apparent, particularly in relation to the second thematic map, was that these initial maps were 'messy' and appeared to lack a coherent structure and internal logic. However this reflected the evolving and responsive nature of the research and I therefore sought to learn from the messiness rather than impose a rigid structure. The next step was:

> *"…to go beyond initial impressions..through the use of structured and diverse lenses on the data…[in order to develop]…a theory with a close fit with the data".* (Eisenhardt, 1989, p.541).

I systematically scanned and wrote familiarisation notes on individual items of transcribed material from workshops, focus groups and interviews, and for each case study as a whole, doing preliminary coding linked to the initial thematic maps in order to iteratively:

> *"….compare systematically the emergent frame with the evidence from each case in order to assess how well or poorly it fits with the case data"* (Eisenhardt, 1989, p.541).

This was a process of 'complete coding' in which I aimed *"to identify anything and everything of interest and relevance to answering [my] research question[s], within [my] entire dataset"* (Braun and Clarke, 2013, p.206). This process involved me testing how well or poorly the initial themes and individual codes fitted with the data from each of my case studies, as well as creating further codes when I identified new themes, concepts and

relations from my initial analysis of the material. So codes were both data and researcher-derived:

> *"Data-derived codes provide a succinct summary of the explicit content of the data…they mirror participants' language and concepts…Researcher-derived codes…are latent codes which invoke the researcher's conceptual and theoretical frameworks to identify implicit meanings within the data"*
> (Braun and Clarke, 2013, p.207).

In keeping with Eisenhard's (1989) approach I first undertook this process within-case and then searched for cross-case patterns. In addition to helping to manage a large volume of data this approach allowed me *"to become intimately familiar with each case as a stand-alone entity…[and] allows the unique patterns of each case to emerge"* (Eisenhardt, 1989, p.540) before then looking for similarities and differences between the two cases. Once I had refined the definition of relevant constructs and assessed the evidence for these constructs and emergent relationships between then within and across cases, I then worked from the codes and coded data to identify broader patterns and themes (Braun and Clarke, 2013), developing a revised coding framework summarised in two new thematic maps (Appendix 15, p.308). These identified central themes of how participation was understood (see Chapter 8), what was required to embed participation in practice and the barriers and challenges to doing so. This last is not mapped as it broadly mapped onto one of my initial maps (p.307). I then compared this revised framework with the literature *"iterating toward a theory which closely fits the data…[and is also] empirically valid"* Eisenhardt, 1989, p.541). Once I had re-coded the data to this revised framework and compared back to my conceptual and theoretical framework I then developed a final coding frame, included in Appendix 16, and went back through all the coded and collated data to make sure this worked in relation to all my material and the themes which had emerged from the literature and initial analysis as being most important in answering my research questions. It is this final analysis which underpins Chapters 8 to 11.

4.8.3 Involving collaborators in the analysis process

As well as validating my conclusions against theories in the literature I wanted to work with case study stakeholders and in the roles of *"critical friends and validation groups [who would] consider [my] criteria and standards of judgement"* (McNiff and Whitehead, 2009, p.63). I hoped that the analysis would be underpinned by collaborative sense-making as part of an ongoing process of action and reflection. As outlined in 4.2, there are inherent tensions between taking an action research approach and the requirements of academic and particularly doctoral research (Herr and Anderson, 2015, McNiff, 2013). But in action research analysis is integrated into learning and reflective inquiry as part of the process rather than as a separate stage, so there was a process of collaborative learning and sense-

making throughout my work with the case studies. So for example in the CCHP workshops participants engaged in reflecting on what they were learning about embedding participation, as well as collaboratively produced outputs including reports and notes (see Appendices 3, 8 and 9). In the YSBNT study collaborative learning and sense-making happened through discussions in young advisor and research team meetings as plans for young people's participation in the study developed and changed. Participants also contributed to the analysis process outlined in stage 6 of Table 2 above at a meeting with CCHP staff and young people to comment on emerging findings, and through input from the Y-SBNT research team and young advisors on a chapter I drafted for the study report to funders on learning emerging from young people's participation.

4.9 Conclusions

Although I approached this as an action research study and certainly *with "participatory intent"* (Greenwood, Whyte and Harkavy, 1993, p.175), in practice only one of my case studies (CCHP) can justifiably be called an action research study. The reasons for this are explored further in the chapters which follow, particularly Chapter 7, which describes the process in the Y-SBNT study. Therefore I would argue that this study was located within a participatory paradigm (Heron and Reason, 1997) informed by an action research methodology. The study was an embedded multiple case study (Yin, 2012) structured around descriptive, organisational cases; both of which were selected because they were in some way unique. The case studies also provided contrasting opportunities to explore researcher positionality as an insider and outsider researcher.

This study focused particularly on extending and challenging existing theoretical perspectives about what it means to embed young people's participation in health services and research. My analysis was based on inductive thematic analysis and Eisenhardt's (1989) paper on building theory from case study research. Key issues which emerged from this process, discussed in Chapters 8 to 11 were: how participation was understood and the implications of this conceptualisation for the embedding of participation in health services and research; how understandings of participation informed organisational culture, structures and systems; and the role these played in enabling participative practice. The chapter which follows discusses the learning from the process of critical inquiry which preceded and informed my work with the case studies.

5. Critical inquiry

Qualitative research is inherently critical, interpretive, and multimethod in function (Watson and Watson, 2011), as well as being a place for critical conversation (Denzin and Lincoln, 2005). Further to this, as outlined in the previous chapter, this study sought to be participative as well to research participation, not least because involving those who are the focus of research has been found to have a positive impact on what is researched and the impact of research findings on policy and practice (Staley, 2009). Participatory research seeks to move beyond consultation to involving the subjects or objects of research in shaping the development and implementation of research studies (Groundwater-Smith, Dockett, and Bottrell, 2015). As discussed in the previous chapter action research aims to produce *"knowledge grounded in local realities that is also useful to local participants*" and responds to *"local realities and needs"* (Herr and Anderson, 2015, p.121). I wanted to design a study with relevance to policy, practice, and the realities of children and young people's participation in health services and research. Therefore in addition to working collaboratively with the two case studies I sought input from stakeholders *"including policy makers and those 'on the receiving end' of policy*" (Torrance, 2011, p.577) in developing my initial ideas for this study. This echoes Friere's (1970) process of 'concientization': collective self-inquiry and reflection which takes the form of dialogues, investigations, and knowledge generation. Nind and Vinha (2013) talk about how Freire saw dialogue as creative and liberating, and how inclusive research (research with 'participatory intent') should include Freire's dimensions of listening (engaging with a range of voices), reflecting (thinking together about those different voices and views) and transforming (learning from and with each other).

In order to ensure that my own 'participatory intent' was part of this study from the outset I undertook a process of critical inquiry during the first year of study, alongside a review of the literature outlined in Chapters 2 and 3. The purpose of these inquiries was to further refine my research questions and methodology, and provide an opportunity to develop and test the ideas emerging from the views of stakeholders as well as existing published evidence. I was interested in how dialogue with those in the field could both enable me to reflect on my own assumptions, and also create something new by seeing it critically and afresh (Freire, 1970). This chapter outlines my process of critical inquiry, key findings and how it informed the case studies which followed.

5.1 The critical inquiry process

5.1.1 Meetings and workshop

In the spirit of action research I sought to gain insights and different perspectives from a broad range of individuals and groups in the field (see Figure 1 below) in order to understand the key issues at play in embedding participation, and to provide an initial focus for the case study inquiries. In addition engaging stakeholders contributed to a deepening and validation of learning which informed subsequent inquiry in the case studies.

Figure 1: stakeholders consulted during October 2012 - July 2013

- Children's Commissioner for England and her policy and participation leads
- Council for Disabled Children and the steering group of 'Making Ourselves Heard' (a project supporting disabled children and young people's participation)
- NHS England
- Children's Rights Alliance for England
- Association for Young People's Health
- Participation leads at the Royal College of Paediatrics and Child Health
- Barnardo's service in Bristol supporting children and young people's participation in the Children's Community Health Partnership (which led to one of my case studies)
- Great Ormond Street young people's advisory group (part of Generation R (GenR, 2016)
- University College London Institute of Education Public Engagement Researchers Network

This consultation involved attending meetings and events with the groups and individuals listed in Figure 1 above to explore people's understandings of what might be required to embed young people's participation in health policy, practice and research. This process culminated in a workshop in July 2013, which I organised around the topic of 'embedding children and young people's participation in health and social care services' (my original research topic). The workshop was organised in collaboration with Investing in Children, Making Research Count, the Children and Young People's Participation Learning Network and UWE. Over 100 policymakers, practitioners, other professionals and young people came along to reflect on the challenges and opportunities for children and young people's participation in the context of wider changes in health and social care in England.

The workshop began with practical examples from children, young people and organisations working with them including Dr Maggie Atkinson, then Children's Commissioner for England, Investing in Children, the Council for Disabled Children, Association for Young People's Health, Young Minds, North Bristol Community Children's Health Partnership and East and North Hertfordshire NHS Trust. I then facilitated discussions on what it meant to embed children and young people's participation within and across health and social care services, and what participants thought might be required for children and young people's participation to be meaningful, effective and sustained at individual, service and strategic levels.

5.1.2 Analysis

In keeping with the action research approach the learning which emerged from my critical inquiries informed *"the development of action strategies and their implementation…[and was] followed by further data collection to evaluate these"* (Noffke and Somekh, 2011, p.96). Learning from the critical inquiries was not part of the material analysed for Chapters 8 to 11, which focus on the two case studies, analysis was therefore less formal and structured. But I used a thematic analysis approach (Braun and Clarke, 2013) to identify the key themes and issues discussed in 5.2 below from meeting notes, journal entries and report and blog posts from the workshop (Brady, 2013) outlined above. Part of the learning from the critical inquiry process was that the original topic of 'embedding participation in health and social care' was too broad, and that both areas merited their own in depth study. This material, along with the literature discussed in Chapters 2 and 3, informed my planning with the two case studies, as outlined in the two chapters which follow. Although the focus of these critical inquiries was on health services, not least because of the lack of forums for researchers involving children and young people in health research (Brady, 2014), the learning below is relevant to children and young people's participation in both health services and research.

5.2 Main points of learning from the critical inquiries

Participation in health services

The report from the workshop (Brady, 2013) and notes from the meetings outlined in Figure 1 above echo much of the literature discussed in Chapters 2 and 3. For example participants felt that the key to embedding was in focusing on participation as part of the everyday practice of individual practitioners. But it was felt that this practice needed to be underpinned by the support of managers, commissioners and national bodies, along with an explicit organisational commitment to participation and children's rights:

> *"For CYP's participation to be embedded workshop participants felt that it needed to be a routine and central part of what…services, organisations and staff do, integral to organisational purpose, structure and processes and fundamental to effective service delivery and CYP's wellbeing"* (Brady, 2013, p.5).

Understanding of participation was thought to vary considerably across health services and often be seen as synonymous with 'listening' and 'consultation'. Participants thought that there needed to be more understanding of how and when these words were used and the meaning behind them, as well as how children and young people's participation fits with the agendas of public engagement and involvement in health. People also thought that the nature of health services would create specific challenges for participation, for example if children, young people and families identify with a particular service that they are using rather than 'health services' or the wider NHS as a whole. This certainly emerged as an issue in the CCHP case study, as discussed in the chapters which follow.

Participation practice was felt to vary considerably across health services, with children and young people more likely to have opportunities to participate in some healthcare environments than others. Changes and restructures within the NHS and health and social care more widely were seen to provide both opportunities and challenges, including some key high-level champions raising the profile of participation nationally and a shift towards local level decision-making potentially providing more opportunities for innovation, but also making it more difficult to share practice. Understanding of and commitment to participation was seen to vary amongst clinicians, with a perception that many health professionals tend to think about health outcomes in a stratified way (e.g. does someone's leg work) rather than the quality of life issues which may matter more to children, young people and their families. This suggests that effective participation could be understood not as literal responses to what children and young people are saying, but by professionals identifying generic issues from children and young people's views and experiences which might challenge practice. Another suggestion was to convince sceptics of the case for participation in terms of benefits for service delivery, e.g. demonstrating that children and young people were more likely to engage with treatment in a service which is seeking to meet their needs by listening to them rather than making assumptions.

However it is a lot easier to talk about these things than to put them into practice and making a clear link between participation and service improvement is far from straightforward. But in the case studies which followed we sought to explore how best to 'make the case' for participation as well as how the embedding of participation could be supported or hindered by the structures, systems and cultures of health services and health research.

Considering who is and is not included

Workshop participants shared innovative work with young people affected by sexual exploitation, disabled children and young people, young offenders and looked-after children and young people:

> *"[There should be a variety of opportunities for CYP to be involved 'in every way and at every level'…while recognising that not all CYP will want or be able to be involved. Several participants suggested starting with…discussions with CYP about their individual treatment or the service they're using, and then extending that to providing opportunities for participation in service planning and delivery as well as participation at a strategic level."* (Brady, 2013, p.2).

Recognising that not all young people want or are able to be involved in participation also emerged as important in the research which followed these critical inquires, as did the idea of building up to strategic and/or collaborative (i.e. group) participation from individual participation. Other issues from the critical inquiries which this study went onto consider was the acknowledgement that much needed to be done for participation to reflect the diversity of children and young people who may use health services, and to make opportunities to participate more visible, accessible and appealing to those who might not normally consider getting involved.

Power and control

The idea of participation in health services needing to be about more than children and young people 'having a voice' (see 2.2.1) came out strongly in the workshop and other meetings. One suggestion was to focus on empowering children and young people to demand better care rather than expecting professionals to initiate change. This balance between professionals and health services providing opportunities and creating an environment in which young people can initiate action was something that emerged gin the case studies.

Discussions of power often appear to assume that the main tension is an adult-child one, that power is something which adults have and can choose to share with children and young people. But participants in the critical inquiry process pointed out that in order to share power with children and young people frontline staff need to feel listened to themselves, that they have a say in service and organisational decisions and are supported to take risks. But: *"the structures and hierarchy within the NHS and other public bodies in particular don't support participation or power-sharing"* (Brady, 2013, p.4). Furthermore children and young people not only needed access to people in power but those people needed to be willing to listen and act on what children and young people were saying.

Feedback, evaluation and some measures of impact and outcomes were also seen as crucial to capturing learning and improving practice within and across health services:

> *"In order to understand how participation is working and how it can be improved CYP's participation should be constantly reviewed and evaluated with input from CYP, staff and organisations…CYP and adults involved [need to] see that something has happened as a result of their participation and feel that their contributions are valued….But organisations should also remain aware that participation is not just about outcomes and change, but also about the quality of the process"*
> (Brady, 2013, p.7).

However it is not always the case that something happens as a direct result of participation, the importance of young people knowing that their contribution has been taken seriously is something this study went on to explore, along with the importance of evaluating the participation process as well as any associated outcomes.

5.3 Conclusions

As the inquiries were opportunistic it was difficult to anticipate at the outset how they would develop, but I found that children and young people's participation in health services and research was an area of increasing interest to policymakers, practitioners and researchers. Many of the themes which emerged from these inquiries reflected discussions in the literature and were echoed in my subsequent work with the two case studies.

People I spoke to during the critical inquiries felt that there was already a lot of existing guidance on participation and that they generally knew what children and young people wanted, but that there were a lack of examples of the realities of participation practice or understanding of how change happens. This was particularly the case at the level of local services, and people reported little knowledge of how policy drivers and guidance on participation were being implemented 'on the ground'. The two chapters which follow outline the two case studies with whom I worked to explore this, and Chapters 8 to 11 present the learning that emerged from this process.

6. Case Study One: Participation in health services

Following the discussion in Chapter four of the case study methodology and selection, this chapter describes the background and context of my first case study: the Community Children's Health Partnership (CCHP). I then go on to outline the development of the research process and reflect on my role within this. The next chapter describes my second case study, and those which follow explore the learning which emerged in relation to my research questions.

6.1 Background: The Community Children's Health Partnership

North Bristol NHS Trust (the NHS Trust) and Barnardo's were jointly awarded the contract for children's community health services in Bristol and South Gloucestershire in April 2009. This contract was a partnership with Barnardo's and provided all the community child health and child and adolescent mental health services (CAMHS) for Bristol and South Gloucestershire. The CCHP had over 800 staff in mental and physical health services including CAMHS, health visiting, school nursing, physiotherapy, speech and language therapy, occupational therapy, community paediatricians and seven specialist services, including an inpatient adolescent unit. These services were previously managed by four separate health organisations. The ambition was to provide equitable and integrated care with a focus on participation and the voice of the child:

> *"The service operates to a set of clear core values, and focuses upon early intervention and prevention… Service user participation is an important part of our service and we are keen to involve children and young people to help us improve the services we offer." (*CCHP, 2014a).

Prior to winning the contract for CCHP the NHS Trust's focus was mainly on acute and hospital-based care for adults, although they did provide some services for children and young people within this. I asked the CCHP participation manager for more information on the background to the setting up and wider context of the CCHP, as this took place several years before my involvement, and her detailed reply to me (Roberts, 2016) is the source of the quotations below. She told me that public engagement or participation in the NHS Trust prior to CCHP *"was focused on adults and had a very limited reach"*, although there was *"…a relatively established patient group…they sat on the fringes of the Trust*" (Roberts, 2016). There was some dialogue with the local community *"but this was more about holding [consultation] meetings with the community than having their involvement with decision making"* (Roberts, 2016) or an embedded culture of participation.

Once the CCHP was established there were attempts to make connections between participation in the CCHP and the wider NHS Trust; Barnardo's had a place on the Trust's patient experience group and presented films and other material on children and young people's participation in the CCHP to the Trust's Board. Executive and non-executive Board members also attended CCHP events with young people but it was felt to *be "relatively superficial as their strategic priorities were different to ours"* (Roberts, 2016). Within the services which came together to form the CCHP there had been pockets of interest in participation, for example a service user participation group in the CAMHS services. But this…:

> *"…wasn't backed up by serious management support so [participation had] tended to focus on getting things like water available in the waiting room and magazines [rather than getting children's input in service design, delivery and policy]. There was a growing interest [in participation] but without any structure. Many services had never evaluated their work or thought to ask families or children about what they thought. In disability services they had historically had parents come to talk at their away days but it was hard to know what to do with the feedback they were given. Most CCHP services had [also] never been tendered before".* (Roberts, 2016)

Barnardo's were subcontracted by the NHS Trust to support and drive service user participation within CCHP services. In contrast to the NHS Trust and the services which came together to form the CCHP Barnardo's has a national participation strategy and an established culture of participation with both communities and individuals:

> *"We [Barnardo's] had been working in this [participative] way as an organisation for a long time and there weren't any cultural barriers or lack of understanding to hinder practice. Being able to work with the most vulnerable and less heard requires us to look at situations differently, which includes listening to what [children and young] people say about what's not working for them in other areas of their life and with other services and try out new ways of working. We don't come from a place where we think the professionals have the answers".* (Roberts, 2016)

The Barnardo's element of CCHP was called HYPE: Helping Young People (and children and families) and aimed to:

> *"…support children and families to have a say, recognising them as experts in their own lives so they can influence how their health services are delivered. HYPE works with both health workers and managers to support this involvement of children and young people"* .(CCHP, 2015b)

The CCHP core stated values were: *"respect for the unique worth of each child and young person, outcome-focused and innovative, child and young person at the centre, accessible and equitable services [and] service user participation at all levels"* (CCHP, 2014c). The related Young People's Charter says that children and young people using CCHP services should:

- *"have a choice of how information is presented and it should be easy to understand and age appropriate*
- *have a right to be treated as individuals and to not be patronised or judged*

- *have a right to be seen by health workers who are welcoming, patient, and understanding*
- *be given the opportunity to change their health worker and where possible be given a choice of male or female worker*
- *have a say in what information is shared and with whom*
- *have a say in arranging their appointments, in places which are clean, comfortable and accessible".* (CCHP, 2016b)

I had heard about the CCHP from a number of contacts during the critical inquiry phase discussed in the previous chapter, and was interested to learn more about this a unique service model in which an NHS Trust and voluntary sector organisation were contract partners. The CCHP had a stated commitment to children and young people's participation from the outset, with a consultation with children, young people and parents undertaken in order to inform the development of the partnership (Roberts, Wright and Goymer, 2008). The partnership was attempting to put into practice many of the ideas I wanted to explore about what it meant to embed participation and was therefore a good model to explore further the reality of embedding children and young people's participation in practice, and look in more depth at what happens between rhetoric and reality.

A note on re-commissioning

The CCHP had been in operation since 2009 but, after the initial five year contract was extended by two years, European law required that the commissioning bodies responsible go through a process of recommissioning. The consultation process for this recommissioning started in 2014 but was delayed and the contract extended again for an additional year, with the new substantive contract planned to be awarded in summer 2016 for an April 2017 start. However in May 2015 the NHS Trust announced that they had decided not to extend the CCHP contract beyond their contracted date of March 2016, and that they did not intend to bid for the next contract. The main reason given for this was that the Trust felt that their strategic direction required them to focus on acute and hospital-based care and that the CCHP service sat outside this. This announcement caused considerable upheaval and resulted in the commissioning of an interim one year 'lift and shift' contract starting in April 2016 (supporting existing arrangements, performance levels and contracts at the point of transfer). This interim contract was awarded in November 2015 to a partnership of three organisations (two social enterprises and one NHS Mental Health Trust). The CCHP kept its name for the interim year and the lead organisation in the partnership continued subcontracting Barnardo's HYPE service. This meant that the planned roll-out of the participation strategy and framework developed during this study continued to happen, albeit more slowly than had been planned. The re-procurement for the substantive contract started in February 2016 and, at the time of writing, the

Barnardo's element of the service was going through a competitive tendering process with project cuts of up to 75%. Bar a workshop to discuss emerging findings in summer 2015 my active work with the CCHP ended in October 2014, so many of these events happened after the end of active fieldwork for this study. Nonetheless the recommissioning had an increasing impact towards the end of the project. It also has longer-term implications for the embedding of participation in the CCHP, discussed further in Chapter 12.

6.2 Initial ideas

I contacted the manager of the Barnardo's HYPE service (the participation manager) and met her in January 2013. We discussed the background to the CCHP and HYPE and agreed that there could be mutual benefits to CCHP being one of my PhD case studies because of the unique, multi-disciplinary and multi-agency nature of the CCHP and the focus on children and young people's participation as central to the partnership. The participation manager suggested that the focus of our work together could be getting CCHP staff and young people involved in developing a more coherent participation strategy, as well as trying to create more consistency across services. We agreed that this would be a good focus for the first phase of an action research cycle.

6.2.1 Early explorations

In May 2013 I was invited to contribute to a CCHP-wide participation event which was attended by over 70 staff, commissioners, six young people and three members of a parent participation group. This event enabled me to gain a wider sense of CCHP and the partnership's commitment to participation, as well as getting more of an understanding of some of the challenges – particularly variations in understandings of participation and commitment to participation across the different services and elements of CCHP. I facilitated a 50 minute session introducing the proposed research and exploring what came to mind when participants thought about 'embedding participation', how CCHP's aims and priorities linked to wider discussions on children and young people's participation in health services, and what my research with CCHP might look like. At the meeting it was agreed that representatives from CCHP and Barnardo's would attend the critical inquiry workshop I was organising that July. We also agreed that I would meet senior managers from the NHS Trust and Barnardo's in July 2013 to plan next steps.

6.2.2 Confirming plans and setting up a 'core group'

Following further discussions with the participation manager and my supervisors, and agreement in principle from the NHS Trust, I met a group of senior CCHP managers in July 2013 at a regular monthly meeting. These managers (the participation manager and

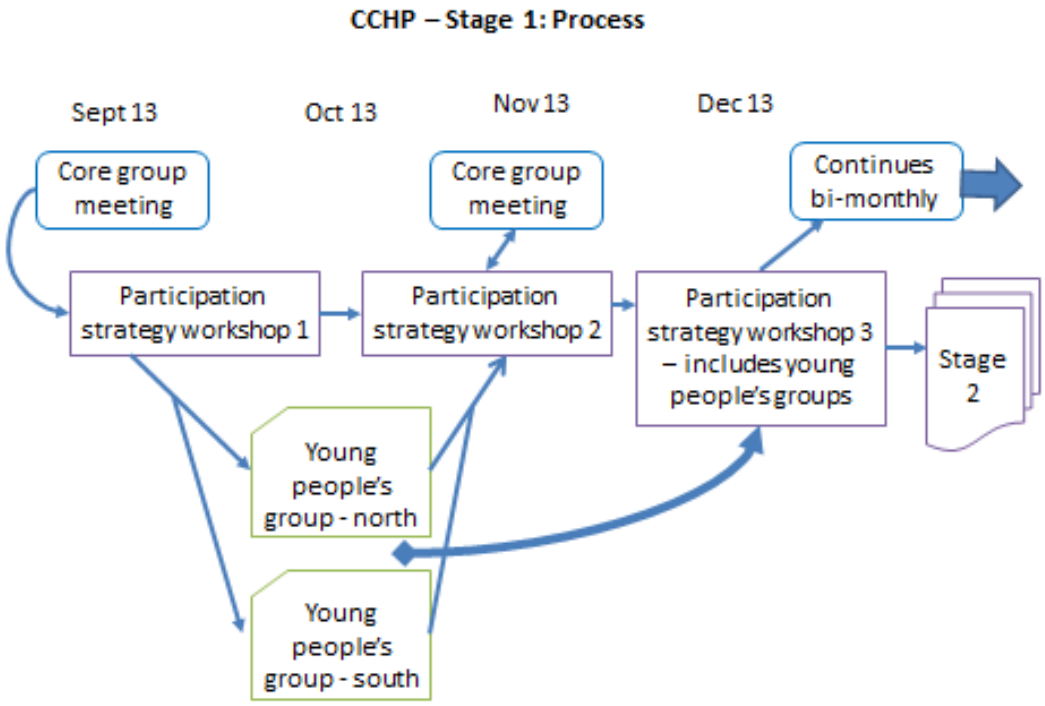
CCHP partnership director, partnership manager, and clinical governance and quality manager from the NHS Trust) agreed to the research going ahead and proposed that those present form a 'core group' for the project. The agreed purpose of this group was to provide CCHP management input as a critical inquiry group, giving continuity and reflecting on emerging ideas and the applicability to the organisation. I attended these meetings by person or by phone throughout the fieldwork period in order to to review activity to date and agree next steps.

Young people were not present at these core group meetings, as they were focused on management issues, and my research was generally only one item on a busy agenda. The work of developing the strategy and framework involved young people and adults working in collaboration, with the core group input often limited to a quick conversation about management and organisational implications of the work in response to an update from me. However there is apparent contradiction in a collaborative project on participation being overseen by a core group of professionals which was never explicitly addressed. In retrospect it would have been good to explore other options such as separate steering group which included young people and adults or to find other ways to involve young people in management of the project. The practical challenge for this would have been finding a way to do this which fitted with professionals' and young people's availability and interests.

6.3 The process – stage 1

The idea was to develop a process, in consultation with the core group, in which staff and service users in the two case studies were actively involved in generating learning as co-enquirers. At the first core group meeting in July 2013 I suggested that this take the form of a number of stages, based on the model of action research cycles, in which I would work with CCHP staff, young people and other stakeholders through workshops and other activities in order to work collaboratively towards practical outcomes and create new forms of understanding. I hoped that this approach would enable us to open up to critical inquiry existing assumptions and practices around participation in the CCHP, and explore the systems and processes required for young people's participation to be embedded effectively. It was agreed that each stage would be focused on a specific issue or service – in the first instance the development of a CCHP participation strategy through a series of workshops with staff from the NHS Trust and Barnardo's and young people who had been involved in CCHP participation activity (see Figure 2 below):

Figure 2: CCHP stage 1 process v1



The initial plan was that the first stage would include workshops with up to 12 staff, and parallel sessions with young people who have been involved in CCHP participation activity. The starting point for the first workshop, agreed with the core group in July 2013, was on how a participation strategy could support the embedding of young people's participation in the CCHP. We agreed that we would explore the assumptions underlying the strategy as well as considering how we could use and operationalise existing participation standards and values to make them relevant and visible to staff, services and service users.

It was intended that the young people's groups would be timed so that the young people could respond to the outputs from the first staff workshop and reflect on their own experience of participation, in order to generate new insights and questions which would then be further explored in the second workshop. In between workshops stakeholders would be encouraged to reflect on the ideas discussed and, if appropriate, put agreed actions into practice. All staff and young people involved would then come together for the final part of the cycle.

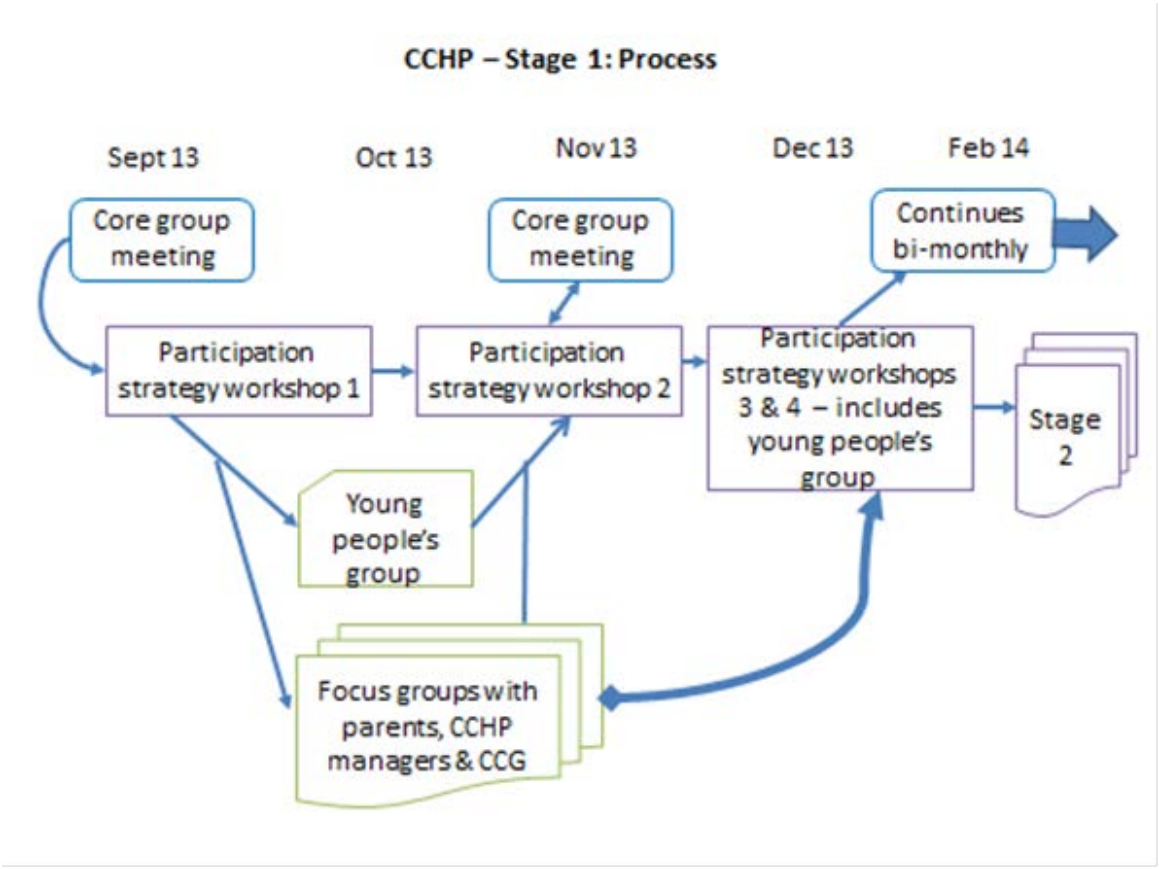
Although it was agreed by the core group, and subsequently by those involved in the workshops, that the stakeholders involved in the project on an ongoing basis should be CCHP staff from the NHS Trust and Barnardo's and young people, we also agreed that it

was important to get input from others with a stake or interest. These included parents, commissioners and CCHP management groups, who were consulted through a series of focus groups. So these participants were research subjects rather than active co-inquirers. During this first stage, between July 2013 and March 2014 there were five meetings of the core group, two workshops with staff, one with young people and two with staff and young people together (one more than originally planned). I also facilitated focus groups with CCHP operational management and clinical governance groups as part of standing meetings, and another focus group with members of a learning disability parents' group.

Being responsive

The plan originally had been to work with staff and young people separately and then bring them together for one final workshop to agree the strategy, framework and next steps. However at the December 2013 meeting there was clear agreement from the staff and young people present that they wanted to meet again for a longer meeting for further discussion on outputs and next steps. As this was a collaborative project in which those involved felt increasing ownership, I felt that it was important to accommodate this request, especially as the original plan had been developed before the group came together. The December meeting had been arranged for early evening to enable young people to attend, but this would not work for a longer meeting as people would be tired after a full day at work, school or college. Therefore the next meeting was scheduled for the next available school holiday - the February 2014 half term. This was positive in the sense that the group felt that they had a stake in the project and were taking ownership of the outputs. But the enforced delay meant there was a lag in the project because of the need to wait over two months for another workshop. This meant that it would have been impossible to go through two cycles of implementing the strategy, so at the core group meetings on January and March 2014 it was agreed that there would instead be one cycle piloting the strategy. The parents' group with whom I had spoken were also keen to have some ongoing input, rather than being a one-off focus group, so I agreed to come back and meet them again in stage two to get their feedback on the draft strategy. Figure 3 below outlines the revised process for stage one:

Figure 3: CCHP stage 1 process v2

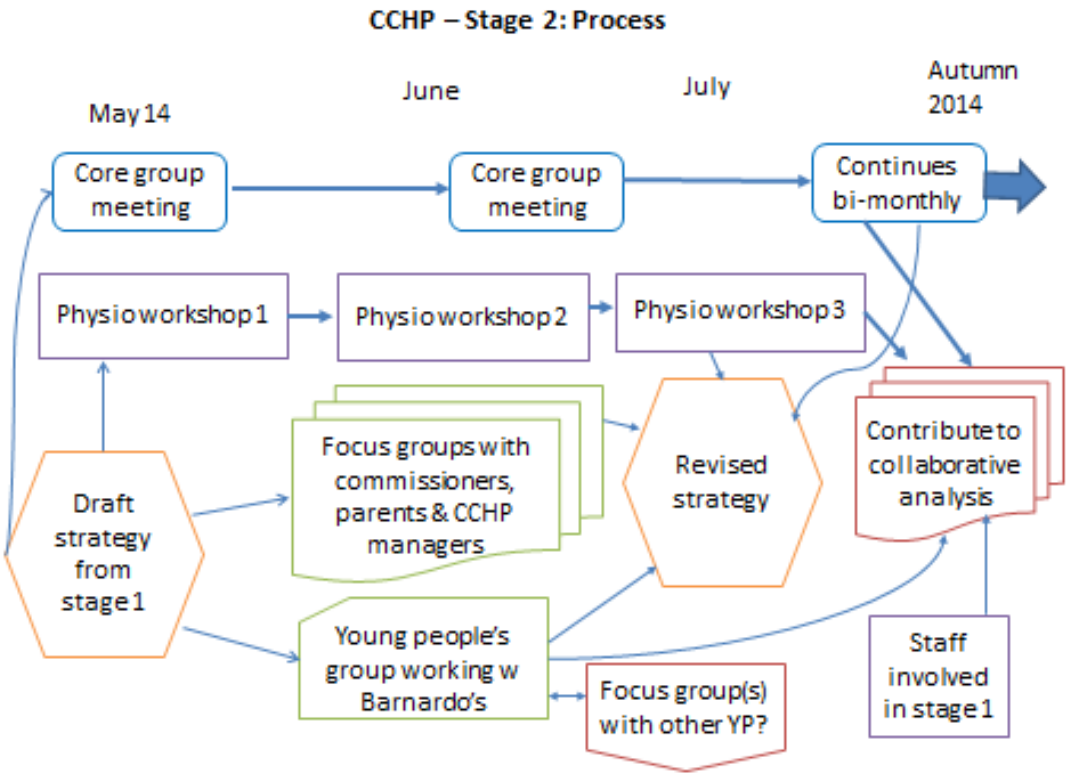


Stage one culminated in a CCHP event in April 2014 with NHS England's Head of Patient Experience, attended by six young people involved in stage one along with commissioners, senior Trust executives, clinical and Barnardo's staff. The event included a presentation on our work on the participation strategy by the young people and Barnardo's staff, as well as others including a showing of 'Our Participation Story', a film on the personal benefits of participation made by two young people involved in the development of the strategy (CCHP, 2014b).

6.4 The process – stage 2

The core element of stage 2 was a second action research cycle supporting the CCHP Community Paediatric Physiotherapy service to put the strategy and framework developed in stage one into practice, and look at what it meant to 'embed' young people's participation into their service. The physiotherapy professional lead volunteered the service and there was a general acknowledgement that allied health professionals (of which physiotherapy was a part) had in the past had less focussed involvement from Barnardo's than other elements of the CCHP. The central aspect of this stage was the work with the Community Paediatric Physiotherapy team, which was structured around a series of workshops, see Figure 4 below.

Figure 4: CCHP stage 2 process



At the first workshop with the physiotherapy team we began by considering where people thought they were in embedding participation in their service, where they wanted to be and how they might get there. In between workshops the physiotherapy team tried to put the strategy and framework into practice, working with members of the Barnardo's HYPE team to try and embed participation in their services. In the second and third workshops the group came back together to reflect on what had helped and hindered their embedding participation in practice and revise plans. During this second stage, between May and October 2014 there were two meetings of the core group and three workshops with physiotherapy staff, a co-inquiry group with the parents involved in stage one and a focus group with CAMHS professional leads. Alongside the work with the physiotherapy team Barnardo's took forward the young people's request at the end of stage one to develop a poster and film, reporting back at the sharing event described below. We had talked about testing out some of these materials with other young people who may not have had prior experience of participation ('focus groups with other YP' in Figure 4 above) but there was in the end not sufficient time to do this.

Other activity included going back to the parents' group from stage one to run a second focus group, as they'd requested a chance to have an input into the development of the strategy. After one meeting was cancelled at short notice, a focus group was arranged with

professional leads in CAMHS services, and this group was facilitated by the manager of the Barnardo's HYPE service around a topic guide which I had developed, as I was unable to attend the meeting. Because of the recommissioning process and people's availability it was not possible to do further focus groups with CCHP managers or commissioners, but in October 2014 I attended a meeting of the Bristol Children and Young People's Network run by Voscur, a charity that provides direct support services and specialist advice to voluntary organisations and social enterprises across Bristol (Voscur, 2016). The Voscur meeting included a presentation by commissioners on plans for the CCHP and also gave me an opportunity to get the views of the wider voluntary and community sector, and commissioners, on my work with the CCHP.

We brought everything together at meeting in October 2014 (the orange hexagon 'revised strategy' in Figure 4 above). This meeting included updates on work undertaken since the end of the first stage in February by some of the young people who had been working with Barnardo's and by the physiotherapy team and reflections on emerging learning, the research process and next steps. The participation manager also announced at this meeting that a supporting budget had been attached to the participation framework to encourage innovation. After this meeting Barnardo's went on to support the CCHP to plan the implementation and roll-out of the strategy and framework, as well as working with young people on the film and poster they had been developing for current and potential users of CCHP services. At the meeting we agreed that I would work with the participation manager and colleagues to write a report on the research process for the CCHP, but this event marked the end of my active engagement with the organisation. I outlined the next stages of my PhD and we discussed ways in which there could be collaboration in the analysis and writing up. A sub-group of staff and young people involved in the earlier stages said they would be interested in being involved, and that the best way to do this would be to arrange another meeting to get people's input into emerging findings. So in June 2015 I came back for meetings with staff and young people, where I presented findings from my initial analysis and sought people's views on how these reflected their experience of both the research process and of working in participation in the CCHP.

I also had further engagement with the CCHP in relation to a report on the project required by the NHS Trust's Clinical Effectiveness Directorate (Brady and Roberts, 2016) and a report (Appendix 8) produced for a presentation on the project at the NHS Expo in September 2015 (NHS Expo, 2015).

6.5 Conclusions

The CCHP was attempting to put into practice many of the ideas I wanted to explore in my PhD about what it meant to embed participation and therefore appeared to be an ideal case study through which to explore the reality of embedding young people's participation in practice. Over the two years we worked together, including the workshops which took place between September 2013 and April 2014, we were able to explore in much more depth and what happens between the rhetoric of participation and the reality.

What all this means in relation to my research questions is considered in the chapters which follow. These consider how participation was understood in the two case studies; how understandings of participation informed organisational culture, structures and systems in the two case studies; and the role these played in enabling participative practice. But before that I will outline the research process in my second case study.

7. Case Study Two: Participation in health research

This chapter describes the background and context of my second case study, which focused on young people's participation as young advisors in the 'Youth Social Behaviour and Network Therapy' (Y-SBNT) study. I then outline the development of the research process and reflect on my role within this and the implications for this study.

7.1 Background

The Y-SBNT study was a randomised controlled feasibility trial, in which I was a co-applicant, which aimed to adapt and pilot a family and social network intervention for young people who misuse alcohol and drugs. The study was funded by the NIHR Health Technology Assessment (HTA) programme, (Study Registration: ISRCTN93446265) and started in June 2013, with the final report was submitted to the HTA in January 2016. In the proposal we stated that:

> *"The project team will actively involve a sample of young people with a history of treatment for substance abuse and a sample of parents of young people with substance abuse problems throughout the research process. At this stage, these key stakeholders will be supported to work alongside the research team in order to ensure that the intervention is acceptable and relevant to our target groups, and reflects the views of service users and their families. The delivery of intensive family interventions outside well-resourced trials has been plagued by problems with retention. By closely involving service users and parents in the design of the intervention, we aim to ensure greater retention of young people and social network members during the intervention delivery as well as contributing to the wider evidence base on patient and public involvement".* (Copello *et al.*, 2012)

7.2 Participation activity

Young people's participation in the Y-SBNT study consisted of a series of young advisor and other meetings in which my fellow public involvement lead and I, along with other members of the research team, worked with young people to explore the principles behind the intervention (social networks, and engaging with services), as well as getting their input into the content of the intervention itself. During the first phase of the Y-SBNT study (the development of the intervention) we sought to actively involve young people with experience of substance misuse services in order to ensure that the intervention addressed the issues faced by young people in treatment. Young people's participation during the development of the intervention focused on ensuring that the intervention was acceptable and relevant to the Y-SBNT study's target groups, and reflected the views of service users and their families. Participation activity in the first research phase, the adaptation of the original adult SBNT intervention (Copello *et al.*, 2009), focused on the nature of social networks and how these may differ for young people and adult users of

substance misuse services, including thinking about the important people in young people's lives and why they might be helpful or unhelpful. In this first phase we also worked with the young advisors to explore what might help or hinder young people's engagement with substance misuse services (i.e. what would encourage or discourage them from accessing treatment) and generated materials used in the adapted intervention. These materials included examples from the young people of processes perceived as important to obtain social network support, good and bad aspects of services, diagrams of their social networks which were used to develop examples in the manual and an open letter from a young person to a family member included as an appendix to the manual (see Appendix 12). In addition, discussions about how to present the intervention to young people and how to introduce the idea of social network support were incorporated into materials used to train the therapists piloting the intervention.

During phase two (the randomised controlled trial) and phase three (analysis and reporting) young people's participation included input into the design of recruitment and training materials and data collection tools, data analysis and interpretation, reporting and dissemination. Young advisors also contributed to a newsletter sent regularly to all Y-SBNT young advisors, co-presented a paper at the November 2014 NIHR INVOLVE conference (Brady, Templeton and young co-presenter, 2014; INVOLVE, 2014b) on emerging learning on young people's involvement in the Y-SBNT study, and co-authored a related article in the INVOLVE newsletter (Brady, Templeton and young co-authors, 2014).

The Y-SBNT study aimed to explore ways in which young people with experience of using substance misuse services could be involved in health research, and hopefully inform other studies seeking to involve less frequently heard young people (see 3.3). In 7.4 and 7.5 below I discuss how our original plans for the involvement of young people in the Y-SBNT study changed over time, but first I want to consider further how my dual role in the Y-SBNT study came about.

7.3 Becoming a participant observer

This case study differs from the preceding one in a number of ways: because it is focused on young people's involvement in health research, and also because of the dual role I had in this study. I had worked with a number of members of the Y-SBNT study team in the past and, in autumn 2011, was asked if I would like to be a co-applicant leading the involvement of young people in the study alongside another independent researcher (the public involvement colleague referred to elsewhere in this thesis). Although I had advised,

and written about young people's involvement in health and social care research (e.g. Brady *et al.*, 2011; Brady *et al.*, 2012; Brady, 2014) my background was in social rather than clinical research, so being part of a study team was a great opportunity to learn and see things from a different perspective.

My role in the Y-SBNT study had initially been solely as a co-applicant but when I was subsequently offered the doctoral scholarship I realised that this provided a unique opportunity to reflect on the process of involving young people in a study of this nature, as well as to contribute to the small body of robust evidence on young people's involvement in health research. I was also very interested in the idea of involving a less frequently group of young people in a clinical trial, in this case young people who had used drug and alcohol services. Y-SBNT provided a particularly interesting opportunity to develop a model of *"involvement of young vulnerable people with complex needs throughout an intervention research project" (*from study proposal). The original plan was that the learning from this case study would emerge from a process of reflection with the young advisors, study team and services involved on the processes and impact of young advisors' involvement in the study. However, as discussed further in 7.5 the reflexivity and responsiveness required by the underpinning philosophy of this study meant that these plans evolved as the study progressed.

I discussed the idea of using the Y-SBNT study as a case study at my initial supervision meeting in October 2012, and my supervisors gave me their blessing to explore things further providing I could get the agreement of all parties involved (UWE, the HTA, Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT) and the study team) and clearly demonstrate which aspects of the overall study were my unique contribution and the relevance to my research topic. At this initial meeting we discussed how I could potentially use an action research approach to explore how young people were involved in the development of the Y-SBNT intervention and other aspects of the research process.

BSMHFT supported my post-application desire to use the study's public involvement as a case study, subject to appropriate ethical review, as there were perceived to be mutual benefits in shared learning and contributing to the wider evidence base on the involvement of young people in health research. It took some time to get formal agreement from all parties involved because it coincided with the timetables for PhD project registration and ethical review, as well as setting up the Y-SBNT study. But full agreement by all parties for my dual role was received from BSMHFT, UWE (through the

project registration, ethics committee and contracts processes) and the HTA via the study team in October 2013.

7.4 Involving young people in the study: initial plans

The initial plan for young people's involvement in the study, as outlined in 7.1 above, was to have an advisory group (YPAG) of 10-12 young advisors aged 12-18, with previous experience of accessing substance misuse treatment services but not currently in treatment. The YPAG is a common model for young people's involvement in health and social care research used by, among others, the Medicines for Children Research Network groups (now affiliated via Generation R (GenR, 2016)), The National Young People's Mental Health Advisory Group (CRN: Mental Health, 2016) the DECIPHer ALPHA young people's group (DECIPHer, 2016) and the PEAR public health group which I had previously facilitated (PEAR, 2010). Our YPAG model also drew on INVOLVE and other guidance on young people's involvement in health research (Kirby, 2004; INVOLVE, 2015), including documents I had co-authored (PEAR, 2010; Shaw, Brady and Davey, 2011). The plan was that the young advisors would be supported by the two public involvement leads (of which I was one) to work alongside the research team. This participation would happen primarily through a series of group meetings held over the course of the study, either in a convenient central location or alternating between the sites from which the young people were recruited. Up to 12 meetings were planned to coincide with key milestones for the study.

We hoped that one or two young advisors would attend TSC meetings in order to ensure that young people's views directly informed strategic study decisions, but that, depending on the wishes of the group, these representatives could change over the course of the study. We also proposed that a small number of parents, unrelated to the young people involved in the study either through involvement activity or as participants, would also be involved in the study through membership of the study Advisory Group. However as the study progressed and the ways in which young people were involved in the study evolved, our plans also had to adapt.

7.5 Involving young people: reality

There were some initial delays in recruiting young people to an advisory group because of questions raised by the NHS Trust hosting the Y-SBNT study about whether recruiting young advisors through their NHS services, as had originally been planned, would require ethical approval. Normally ethical approval is not needed for the public involvement in NIHR-supported research, even when people are recruited via the NHS (INVOLVE, 2016b) but, as young people's involvement in the study was also part of my doctoral study this was

less straightforward. The Trust's view was that incorporating an element of research (i.e. the collection of material which would be used as data for my PhD) would require NHS ethical review if the young people involved were NHS patients. Although recruiting outside the NHS still required ethical review the Trust considered that in this case university ethical review would suffice. To avoid delaying the Y-SBNT study or my PhD we therefore decided not to recruit young advisors directly via NHS services, but instead to work with the voluntary and community sector.

Initially we worked with a national drug and alcohol treatment charity, as they expressed an interest in the study and thought it could be an exciting opportunity for young people who had used their services. After discussions with the charity we agreed that we would base the young advisors group in London, as that was the centre of their greatest concentration of young people's services, and information was duly sent out across their network. We asked services to identify young people who have been through treatment but with whom they were still in contact, for example young people involved as volunteers, peer mentors or on service advisory groups. Recruitment started in July 2013, with the first young advisors meeting planned for September of that year. However initial recruitment proved a lot slower than we, or the charity, had anticipated, and the first three meetings (in September, October and December 2013) were poorly attended. At each four to six young people were expected but only two attended on the day, and the young people who did attend varied from meeting to meeting so we did not have the same young people each time. This challenged our assumptions about young people's motivations for participating, as well as instigating a process of reflection with young advisors on how we could involve them better, both of which are explored further in the chapters which follow.

7.5.1 Revising plans for young people's participation

By early 2014 we realised that the traditional format of a single-location advisory group would not on its own be the right model for working with the young people we wished to engage. We hoped to retain a core group of young advisors who would have some ongoing participation throughout the study, but realised that this group would be smaller and more flexible than had been originally anticipated, with ongoing recruitment and young people able to move in and out of the group depending on their availability, circumstances and interest in different aspects of the study. Young people's participation was no longer centred on regular meetings in London, but started with smaller meetings based at services or other locations familiar to young people, as well as email, text messages, post and phone conversations when this was more convenient for the young people or timely for the study (for example, if young people's input was needed in between scheduled

meetings). If interested young people were then given the option of ongoing involvement and invited to become a young advisor, but there was no obligation to do so. We hoped that this more flexible approach would give young people, and services, a chance to find out more about the study and potential participation without making an on-going commitment at the outset. We also sent out regular newsletters to all young people with whom we were in contact so that, even if they were unable to be involved for a period of time, they were kept informed (example in Appendix 10). This new approach led to the participation activity summarised in Table 3 below.

Table 3: Summary of Y-SBNT young advisor activity after changed approach

Date	Activity
January 2014	Consultation meeting in the West of England, attended by three young people, one of whom continued to be involved for the remainder of the study, mainly on a one-to-one basis.
March 2014	Consultation meeting at a service in Oxfordshire with two young people. This led to two completed young advisor applications and both young people saying they wanted ongoing involvement, but this did not materialise despite following up with both the young people and the service.
April 2014	Piloting questionnaires with two young people in the West Midlands led to one young person expressing an interest in ongoing involvement. She was then involved on an ongoing basis, mainly one-to-one but also attending one meeting with other young advisors, and contributed to the chapter on public involvement in the study report.
Spring 2015	Contact with a one of the clinical sites for the feasibility trial where project workers were really enthusiastic about supporting young people's participation. This resulted in two workers accompanying young people to three Y-SBNT young advisor meetings during 2015: four to a meeting at Birmingham University in April, three to a meeting in York in September and two to a meeting in York in November.

Another factor which affected how and when young people were involved in the study was that many of them were also working, often in low-paid jobs for which they would not be paid if they did not work, or from which it was difficult to take time off. In many YPAGs young people are given a gift voucher for their time and this was the model we initially adopted: all young people involved received reimbursement of travel expenses and a £20 voucher for each meeting attended. However when we realised that we were going to have fewer young people involved in the study, and that loss of income was a barrier to participation for some, we decided to adopt a different approach. After considering

INVOLVE and other guidance on payment for public involvement (INVOLVE, 2016c) the trial management group (TMG) agreed in September 2014 to offer young people involved in the study on an ongoing basis payment at a rate of £10 per hour for participation activity, plus travel and subsistence expenses as before. The time needed for any work undertaken remotely (such as commenting on draft documents, or, writing sections of articles and reports) was negotiated in advance. Payments could be in the form of shopping vouchers as before or be paid directly into a bank account via a claim form. Young people could also choose not to accept payment. If young people were working they were advised that this income would need to be declared for the purposes of tax and NI, and that it was their responsibility to do this. If they were claiming benefits they were advised about the necessary rules on earnings and signposted to relevant guidance and sources of information on these matters. One young person was supported by the NIHR Benefits Advice Service for Involvement to manage issues around payment for participation and benefits.

In total 17 young people were involved as young advisors in some capacity, as summarised in Figure 5 below.

Figure 5: Summary of young people's participation in the Y-SBNT study

- The young people came from five areas of England (the West Midlands, the North East and West of England, London and Oxfordshire).
- The 17 young people included 12 females and five males, ranging in age from 16-21 with an average age of 18.
- We met ten young people once, five twice, and two on five or more occasions.
- Over the course of the study we held a total of 20 face-to-face meetings with young people. In between meetings contact was maintained by post, text messages, emails or phone calls depending on the preferences of the young people involved.
- Seven newsletters were sent to young people during the course of the study with updates on the study, information about how young people had been involved and upcoming opportunities.

7.5.2 Involving young people in the trial steering committee (TSC)

In early 2014 we also reviewed our initial plans to have young people as lay members at TSC meetings. The emerging model of young people's involvement did not have the planned core group of young people engaged with the study regularly on ongoing basis, who would have an understanding not just of the study itself but some insights into the process and management of randomised control trials. It was felt by the TMG that this

would have made it more difficult to make any involvement in the meetings accessible and meaningful for lay members. I also had concerns that, without significant changes to the way in which TSC meetings were run, any lay involvement would not be meaningful and could potentially be tokenistic. We therefore agreed that I or my fellow public involvement lead would report to TSC meetings, but offer young advisors the chance to contribute to this report, as well as supporting them to attend TSC meetings if they wished to do so, in which case we would have sought to make the meetings more accessible. However the one young person who did express an interest in coming to TMG and TSC meetings was then unable to do so due to ill health.

7.5.3 Revising plans for this study

As the study progressed and the original YPAG model did not work for the young people we were seeking to engage, the ways in which I had planned to generate learning changed considerably. The absence of a core group of young advisors involved in regular face to face meetings meant that my early idea of collaborative workshops bringing together young advisors and the study team was not possible. Therefore for much of the study the main forum for discussion and reflection on young people's participation in the study was as an agenda item at TMG and TSC meetings, when myself and my fellow public involvement lead would update the rest of the team on activity, seek their advice on next steps and agree changes to our plans for participation. As the study progressed the focus of our work to involve young people in the study shifted towards the emerging learning from our attempts to do this, as opposed to the main source of learning for this PhD being work with a core group of young people established early on in the study. In my ethics application I said that *"as the study develops, and perhaps offers a range of new or different opportunities for partners and stakeholders to become involved, I will…establish (rather than assume) consent for these changes".* Recordings and notes of TMG and TSC discussions about young people's involvement were made to ensure accuracy of my notes but were not transcribed or used to provide verbatim quotations. However, in the absence of the 'dedicated participatory inquiry workshops' I had originally envisaged in my ethics application, I needed to find another way to collect material which could be transcribed and used for this purpose. I ran short focus groups in a TMG and a TSC meeting, as this was the only practical way to get people together for a face-to-face conversation. Although not formal action research workshops they nonetheless provided the opportunity:

> *"…for reflection on the dynamics of participation and learning in practice…[and] consideration of impact and outcomes of involvement…[as well as touching on] issues of power and organisational cultures, and the relationships between professionals and the young people involved".* (Application to UWE Faculty Research Ethics Committee, 2013)

The TMG and TSC focus groups marked the end of my formal PhD fieldwork with the research team, and my input into the study from then on was in my role as public involvement lead. However I have used learning and material created with the young people involved right up until the end of the study, as much of the work in the final stages (writing the study report) generated important learning on the dynamics of participation in the study. This included telephone interviews with the two young people with the longest involvement in the study, as neither was at the time able to come to a face-to-face meeting. These interviews were used to inform the chapter on young people's involvement in the Y-SBNT study report, as well as providing material which informed learning for this PhD. At the young advisor meeting in April 2014 we included a 'river of experience' exercise (Percy-Smith, 2011) in which we updated young people new to the study on what we had done to date and then moved on to a discussion about how they might like to be involved in the rest of the study, as well as what they thought young people's involvement could look like in future research. At the next and final young advisors meetings we looked at the draft public involvement chapter in the study report, including the contributions from the two young advisors (one of whom was at the meeting) and the suggested model for young people's participation in future studies. The additions and changes young people made to this again informed both the chapter in the study report and material on which I drew for my analysis.

7.6 Conclusions

The Y-SBNT study sought to demonstrate the feasibility of recruiting young people to a specifically developed social network-based intervention, and to explore ways in which young people with experience of using substance misuse services could be involved in a study of this nature. It provided a unique opportunity to reflect on the reality of young people's involvement in health research, particularly as participation evolved in response to the challenges and realities of involving young people who are less frequently heard. The implications of all this for the embedding of young people's participation in health research is considered in the chapters which follow. These explore how participation was understood in the two case studies; how understandings of participation informed organisational culture, structures and systems in the two case studies; and the role these played in enabling participative practice.

8. Understanding Participation

This chapter, the first of four on my research findings, draws on my work with the two case studies to consider how young people's participation was understood and the implications of this conceptualisation for embedding participation in health services and research. The three chapters which follow then explore how understandings of participation informed organisational culture, structures and systems (Chapters 9 and 10), and the role these played in enabling participative practice (Chapter 11).

A note on quotations

Quotations from the CCHP case study are mainly from the workshops outlined in Chapter 6. The first cycle centred on two workshops with staff (1.1 and 1.2) and one with young people (YP workshop) and two in which staff and young people came together (1.3 and 1.4) along with some other meetings and groups (see Figure 4, 6.3). The second cycle centred on three workshops with health professionals (2.1, 2.2 and 2.3, see Figure 3, 6.4). CCHP quotations identify the event or document from which they came and whether the speaker is a young person or a participation or health professional. It was not possible to identify and assign codes to individuals from transcriptions of large group discussions.

Quotations from the Y-SBNT study come from discussions with young people, two of whom made individual contributions and are identified as young advisor A and B. Where members of the research team are quoted they have been assigned individual identification codes, as this material comes mainly from two focus group discussions at the end of my research so it was possible to identify individuals in the transcriptions and assign codes accordingly.

8.1 So what does 'participation' mean in practice?

As outlined in 1.2 and 2.2.1 the terminology of participation can be opaque, and this opacity may reflect conceptual differences or confusion which can impact on participation in practice, and on young people's experiences of participation. As the focus of my work with the CCHP was on embedding participation in their services I began by engaging the staff and young people with whom I was working in thinking about what participation involved. The first activity in both the initial staff and young people's workshops was a photovoice exercise (Percy-Smith, 2011) in which workshop participants were asked to select a photo which captured something about what participation meant to them. They then discussed these ideas in small groups and presented them for discussion:

Figure 6: CCHP staff workshop 1.1. Understandings of participation 1

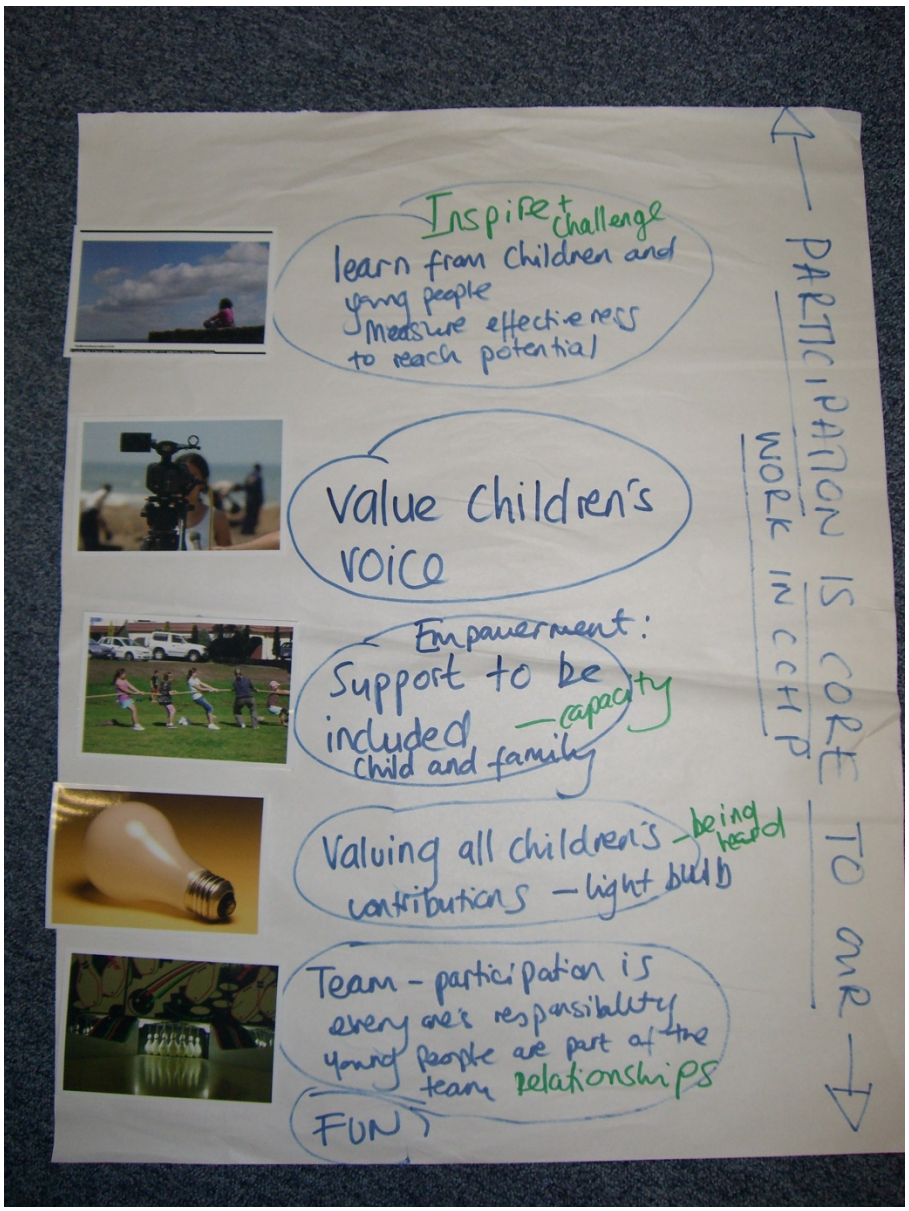
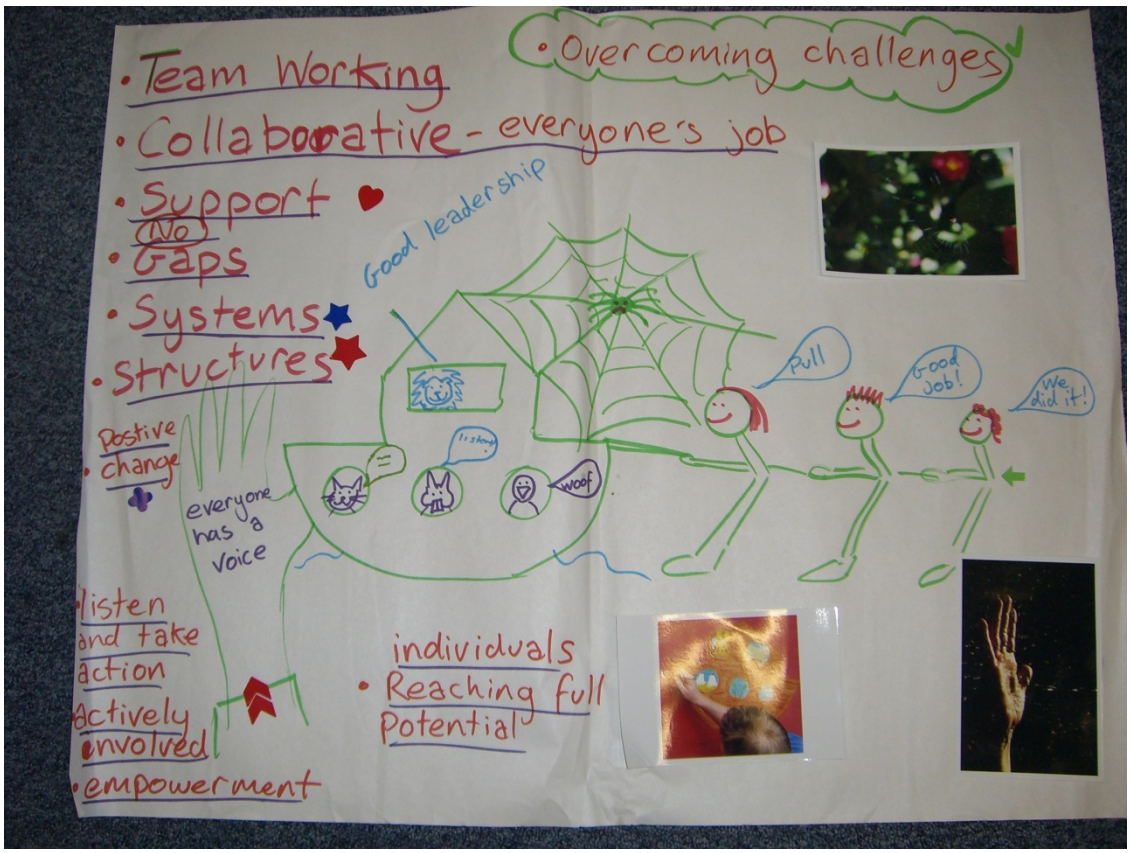


Figure 6 above, from a group in the first staff workshop, highlights a number of ideas around participation as a relational process including shared learning, inclusive practice, capacity-building and shared responsibility. Along the side of the flipchart the group highlighted how they thought participation should be 'core to our work' and embedded in everyday practice.

Figure 7: CCHP workshop 1.1. Understandings of participation 2



As with the previous figure Figure 7 above, produced by another group during the same photovoice exercise, highlights understandings of participation as a relational process including ideas of system, structures and leadership. Both Figures 6 and 7 reflect group discussions about participation being about culture as well as process, and the importance of young people being listened to and respected as well as being actively involved in decision-making. This led to us agreeing the following working definition, included in the CCHP participation strategy:

> *"Participation is a process **and culture** in which children and young people are **listened to, their opinions respected and they are actively** involved in decision making which brings about change in themselves, their peers, the services they use and their communities".* (CCHP, 2015b, p.4).

The emboldened additions expand on the standard definition of participation (e.g. Kirby *et al.*, 2003; Tresder, 1997; Participation Works, 2010) by including culture as well as process and adding listening, respecting opinions and the need for participation to be an active process. These additions sought to imply an understanding of participation which was about more than young people 'having their voices heard' or being consulted, and moving towards a more active participation with young people working in collaborative relationships with adults (Percy-Smith, 2016). But this definition still implies that the scope for young people's influence is largely determined and controlled by adults (Boyden and Ennew, 1997), something I will come back to later on in this thesis.

Figure 8: CCHP YP workshop 1.1 - understandings of participation

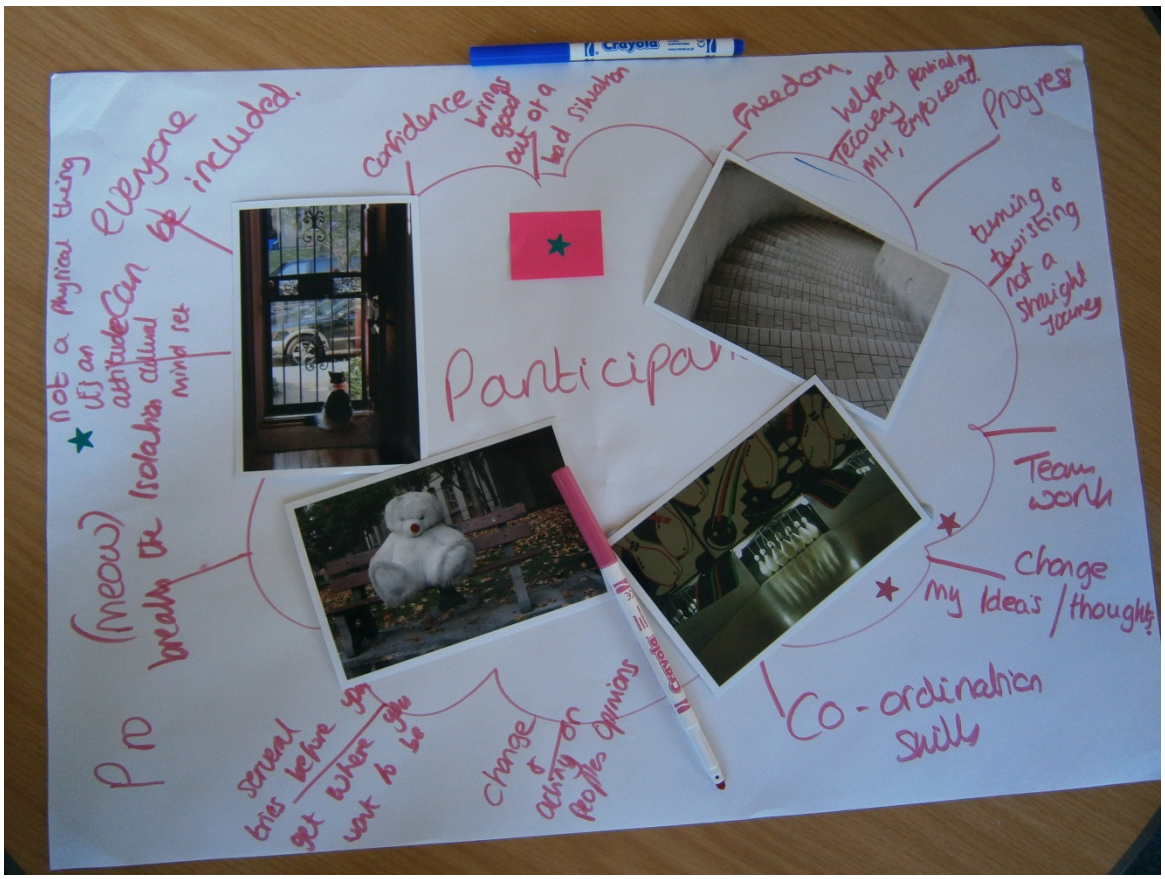


Figure 8 above illustrates how young people in the CCHP conceptualised participation as needing to be meaningful and lead to change, be inclusive and have benefits for young people as well as services, which echoes the existing literature. But the comments about breaking isolation and helping recovery suggest some new insights into the benefits of participation for young people who may be deemed vulnerable, discussed further in 11.3. The comment about *"turning and twisting not a straight journey"* on the right refers to the picture of the staircase and the young people's experience that participation was not an easy or a straightforward thing to do well. They but did not explicitly address the issue of whether they thought their influence was largely determined and controlled by adults, but did agree that good participation needed to be a process in which young people were involved with adults in collaborative learning and developing practice.

The focus of my work with the Y-SBNT study, in my role as public involvement lead, was on how young people's participation could best inform the research. There was little discussion about the conceptualisation of participation in the initial stages of the study. Instead there was an expectation that public involvement in research funded by NIHR bodies would be based on the INVOLVE definition of: *"research…carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"* (INVOLVE, 2016a). Young people's participation in the study was therefore conceptualised as meaning that they

would be actively involved in the research process, including the development of the intervention, which would be piloted with another group of young people (the trial subjects/participants). As with CCHP this was an understanding of participation in which the scope for children and young people's influence appeared to be largely determined and controlled by adults (Boyden and Ennew, 1997). The discussions amongst the research team during the development of the proposal were around how we could best support young people's participation in the research process within this understanding, based on the idea of the YPAG model of involving young people in health research. It was only once the study was underway, and we realised that the YPAG model was not working for the young people we wished to engage, that the research team engaged in critical reflection of the established wisdom.

In the CCHP we started by conceptualising participation based on established practice, and in the Y-SBNT study reflecting on the conceptualisation of participation was something that happened later on, when we had gained experience of supporting the participation of the particular group of young people we wanted to involve. However in both case studies understandings of participation were informed by an awareness of different levels of participation, as individual young people in relation to their own care and collective or strategic participation. Both also highlighted the role of children's rights in understanding participation, and identified potential conflicts between participation and protection rights and the role of adults as gatekeepers and facilitators of young people's participation. Understanding these elements was an important precursor to reflecting on what it means to embed participation in health services and research, and they are explored in turn below.

8.2 Different levels of participation

Young people's participation can be constructed in relation to two main dimensions, the first being involvement in individual or strategic decision-making (e.g. Kirby *et al.*, 2003), focused on *what* young people are involved in. The second is individual or collective participation (McNeish, 1999), focused on *how* young people are involved. The standard model for young people's involvement in health research is one of collective, strategic-level participation through YPAGs. In the Y-SBNT study all participation was 'strategic' in the sense that it was about young people's involvement in the research process and the development and piloting of an intervention, but participation involved working with young people individually (i.e. one to one) as well as collectively in YPAG meetings.

In the CCHP the conceptualisation of participation was generally expressed in terms of individual or strategic-level participation (i.e. young people being involved in decisions about their own care or treatment or informing policy, strategy and service delivery). As the purpose of the organisation was the delivery of health services for children and young people, the participation of individual children, young people and their families in decisions about aspects of their own care and treatment was a key focus:

> *"Participation [can be] a tool to empower children to take control and make informed choices in relation to their own health and care. This could also be linked to person-centred planning".* Notes from CCHP staff workshop 1.2

> *"In terms of Physiotherapy…we work very closely with families and parents, in fact for some groups of children we will be seeing them almost on a weekly basis. We…are setting goals…collaboratively already with parents or with carers…and of course that is participation".* Health professional, CCHP staff workshop 1.1

Another participant talked about how individual-level participation in health services can help to develop young people's capacity for more strategic participation:

> *"People needed to be empowered and feel empowered…whether that is in their day to day care, so they are feeling empowered towards making decisions…or whether that is acquiring knowledge and experience and skills to take part in other forms of decision-making within services, so it is about building people's capacity to be included".* Participation worker, CCHP staff workshop 1.1

This quotation makes the point that young people may need support and encouragement to be involved in strategic participation, but also raises a number of issues around power and control. The participant appears to assume that the act of being involved is inherently empowering for young people. There is also an implication that participation is about young people having a voice in adult decision-making processes for which they need specific 'knowledge, experience and skills', rather than a more collaborative and young person-centred participatory practice (Malone and Hartung, 2010; Percy-Smith, 2016). Issues of power and control are discussed further in Chapter 11, but the above quotation illustrates how individual and strategic participation can be linked and also how understandings of participation can inform practice.

Participation at a strategic level can also inform individual participation, as when one of the young people involved in the Y-SBNT study talked about how her involvement had made her realise how few opportunities she had had for individual-level participation as a service user:

> *"I really liked how I'm being heard for once [as a young advisor in the Y-SBNT study]…I've been in many services where I've had to bite my tongue or I'm just not being heard, and I've not got that freedom of speech the way I should".*
> Y-SBNT young advisor A, phone interview

This suggests that awareness of rights and self-realisation can help build capacity for participation, as well as the idea of involvement in strategic participation contributing to

building capacity for individual participation. In a discussion in the first workshop I did with young people at the CCHP this also came up in a conversation about what participation meant to them:

> *"[Participation is]…something that has benefits for young people as well as services, empowering and helping with recovery".* Notes from CCHP YP workshop 1

This appears to be a different meaning of empowerment to the one at the bottom of the previous page, rather than being something in which power is given by someone (adult/professional) who has it to someone who does not (young person) this suggests 'self-empowerment' i.e. the ability of the individual young person to take control of their situation rather than professionals doing so.

As well as the case studies being very different in nature, as a health service provider and a research project, they also differed in terms of the young people involved. Young people involved in my work with the CCHP were recruited by Barnardo's because of theie prior experience of participation and came from a range of CCHP services. In the Y-SBNT study we sought to involve young people on the basis of their experience of a specific type of service, rather than any prior experience of either participation in the services they had used or public involvement in health research. Therefore the focus of the latter was more on the participation of young people "*as members of a…community of interest"* (McNeish, 1999, p.194) informing the development and delivery of the research study, rather than their participation in individual-level decision making in the services they used. In the Y-SBNT study the preconceived conceptualisation of participation in the study as a 'one size fits all' YPAG approach was challenged by the realities of practice:

> *"Perhaps that sort of [young people's advisory] group structure isn't going to work with these sorts of young people in a project like this. I think it is good to have a group and people fire off each other…but I still think the individual-level stuff that we've had has…worked well and in a more natural way and perhaps this group need that level of support".*
> Research team member E, Y-SBNT TMG focus group

One Y-SBNT young advisor was involved solely on an individual basis, as this worked better due to her geographical location and availability. But some young people expressed a preference for group meetings, and others moved between individual and collective participation depending on their personal circumstances, availability and health:

> *"Although I couldn't come to that [recent young advisors'] meeting due to my mental health I do like how, if I can't come to a meeting, we can have a phone call instead or you're just a text [message] away, or we can do stuff by post. I've not always been well enough to come and see people face to face but that doesn't mean I couldn't be involved in things, whereas some organisations I've been involved with would have said 'you're ill or you couldn't come to a meeting so you can't be involved'."*
> Y-SBNT young advisor A. Phone interview

The flexibility helped this young person to feel valued and supported and was key to keeping young people involved in the study:

> *"This other model [of young people's participation developed during the study] is …a break from the usual [YPAG] scenario and maybe…[participation] shouldn't be a structured thing…it should be reactive and it should develop over time to some degree… [and] there's the potential for it to be more individual based."*
> Research team member E, Y-SBNT TMG focus group

In both case studies conceptualisations of participation shifted over time, and there were not clearly delineated distinctions between individual, strategic and collective participation. At times participation involved a focus on a young person's own care pathway, and on other occasions on wider collective participation to inform service improvement or provide a strategic rationale for participation. For example Barnardo's had worked with parents in the CCHP to gather stories of families of children and young people with particular health conditions, which were then used in work on care pathways in order to give clinicians an understanding of people's journey through accessing services, receiving a diagnosis and further involvement from the relevant professional teams, as well as new insights into the 'patient journey' beyond their services (CCHP, 2016a):

> *"Sometimes some of those [care pathway] stories, just telling the right person that story can influence so much change… and it's actually creating change beyond CCHP because, with cerebral palsy, so much of it is what's happening in the hospitals, that gap before people come into [our] community health services"*
> Participation worker, CCHP staff workshop 2.3

In this instance individual participation informed service development and strategic policy, illustrating again how some blurring between different levels and dimensions of participation could be helpful. The young people involved in the CCHP study also made little distinction between individual and collective participation, appearing to see them as just different ways of 'having a say' rather than different ways to be actively involved in change processes; the film (CCHP, 2015a) and other materials they developed focused on young people as users of CCHP services. It was also acknowledged, as in the Y-SBNT study, that the group format did not work for everyone:

> *"Some of the young people [involved in CCHP participation workshops] find it difficult [to talk in a group]… It's nice for everyone to meet but when they actually can't say their name you have to question whether they going to be speaking freely about their feelings and their attitudes towards something like a [participation] strategy?"* Participation worker, CCHP staff and YP emerging findings meeting

For some young people individual participation was a way to build their capacity to be involved in more strategic or collective participation, for others participation at a strategic level enabled them to gain confidence to have a say on an individual level. Both individual and collective participation (e.g. through one off events) can feed into strategic, and later

chapters consider the learning which emerged from my case studies on how to facilitate and embed participation in NHS and NIHR systems.

8.3 Framing participation: rights and values

8.3.1 Embedding children's rights

In addition to the central role played by different understandings of participation in health services (McNeish, 1999) and research (Clavering and McLaughlin, 2010), beliefs and values held about children and childhood influence assumptions about young people's competence and rights, and whether and how they participate. From the outset CCHP participants conceptualised participation in the context of children's rights and article 12 of the CRC, in relation to young people having a right to have a say in decisions that affect them:

> *"I like how [the strategy] is underpinned by the children act, the UN convention, it's in the core values, you can't ignore it. It's not optional".*
> Health professional, CCHP staff workshop 1.2

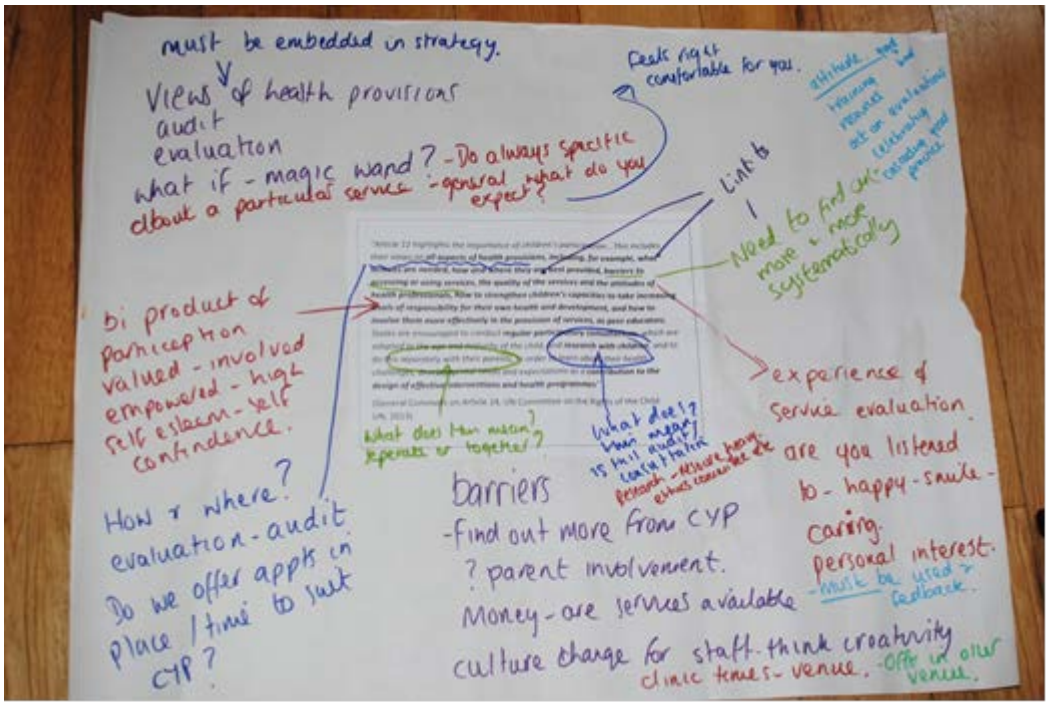
> *"How do we ensure that young people's rights and the way that clinicians deliver a service give young people the opportunities to be empowered, fully involved in their healthcare?"* Health professional, CCHP staff and YP workshop 1.4

This last quotation highlights the importance attached by participants to not just paying 'lip service' to children's rights but ensuring that these rights underpin practice. They also highlight the common understanding that 'children's rights' refer to autonomy or participation rather than welfare or socioeconomic rights (Hammersley, 2015). Vignette 1 below outlines the work CCHP staff did together looking at the implications and applications of the CRC in their services.

Vignette 1: Taking a rights-based approach to developing a participation strategy

In 2013 the UN Committee on the Rights of the Child released a General Comment on Article 24 of the CRC which emphasised *"the importance of approaching children's health from a child-rights perspective"* and that signatories to the convention were expected to seek the views of *children "on all aspects of health provisions…and conduct regular participatory consultations…as a contribution to the design of effective interventions and health programmes"* (UN, 2013, p.7). At the second CCHP staff workshop (1.2) I brought the excerpt from the General Comment quoted in 2.3.2 as a starting point for a discussion on what a rights-based approach to participation might look like in practice. Workshop participants were given copies of the excerpt and asked to spend a few moments discussing this in small groups, before sticking it on some flipchart paper and annotating to indicate what they thought was particularly relevant to the embedding of participation in the CCHP (see Figure 9 below):

Figure 9: CCHP exercise on Article 24 General Comment



Key points of learning arising from the workshop included:

- *"The need for consistency across CCHP is key to embedding participation, and needs to be underpinned by a strategy which sets the culture and ethos for participation*
- *Participation is not consultation, but meaningful involvement which gets reviewed, fed back and can be demonstrated to lead to change*
- *The organisation needs to be robust enough (at organisational, area, service and individual levels) to hear and respond to what children say without being defensive*
- *Going beyond feedback and 'patient voice' and asking children what they need or would like beyond or instead of existing services*
- *Child-centred working and not underestimating children's capacity to be involved*

- *Inform all current and potential children using CCHP services about their rights, and empower children to take control and make informed choices in relation to their own health and care"* (CCHP notes from workshop 1.2: see Appendix 6)

How these points played out in practice is explored further in the chapters which follow, but this work was central to the development of the strategy and framework which emerged from my work with the CCHP. The first 'participation value' listed in the CCHP participation strategy is *"children's right to be heard*" and the strategy (CCHP, 2015b, Appendix 7) cites the General Comment in the introduction:

"[Children should] Participate in decisions about their health care and influence the services they receive. Children and young people using CCHP services will experience:

- *Responsive staff who understand the importance of listening to children*
- *Frequent opportunity to give feedback and make choices*
- *Clear information that meets differing needs".* (CCHP, 2015b, p.3).

[End of vignette]

CCHP was a cross-agency initiative which drew on the expertise of a voluntary sector organisation with extensive knowledge and commitment to children's rights. But in practice, even with a group who had a good understanding of and commitment to, children's rights people were not always clear when and to whom these rights applied:

> *"How do young people know what ages they have the [CRC] rights at? Some children can be fully…mature at the age of 7. [But]…if they've got a special need [or]….disability…have they still got the rights?…they might not be able to understand. They might not be able to access, to have rights like we've got."*
> Young person, CCHP Staff and YP workshop 1.4

This quotation was from a young disabled person who had quite a lot of experience of both individual and strategic-level participation, including participating in three of the workshops I facilitated. But she was still unclear about the universality of children's rights and how this applied in practice. This raises some important issues, which I will come back to in the chapters which follow, about the balance in embedding participation between raising awareness of rights and providing opportunities, as well as questions about inclusion and diversity and who gets to have a 'voice'.

In the Y-SBNT study some people saw young people's participation as a very clearly-delineated, consultative role in response to researcher-initiated activity:

> *"I was very much hoping at the outset…that there would be a very specific protocol for involvement that would be asking people, on a kind of time-limited and task-limited basis, to do a particular piece of work…rather than expecting people to be involved in something on an open-ended basis…to be involved in the study right the way through…so you get somebody to come along and…comment on the treatment manual and that's it, or look at a part of the protocol, the recruitment, comment on that and that's it".* TSC member A, Y-SBNT focus group

However for others participation meant a lot more than this:

> *"I envisage embedding [participation] meaning that [the young people are] there and part of the team… [young] people who are there right the way through the entire journey".* Research team member F, Y-SBNT TMG focus group

These understandings of participation in the Y-SBNT study as, on the one hand, professional-led and consultative, and on the other, more collaborative reflect some of the debates about typologies of participation and how these relate to issues of power and control (e.g. Cornwall, 2008). The appropriate level of participation may have been determined to a large extent by the circumstances of the young people involved (Kirby *et al.*, 2003), but the quotations above suggest a depoliticized understanding of participation (Nolas, 2015) determined by adults. Paying 'lip service' to children's rights does not necessarily equate to meaningful participation of young people in research (Kellett, 2010) or critical reflection on the implications of these rights in the practice of participation. These issues are explored further in the chapters that follow, as is the question of whether paying "*closer attention to who is participating, in what and for whose benefit"* (Cornwall, 2008, p.269) is key to embedding participation.

There was also an acknowledgment of statutory incentives to consider both participation and protection rights in relation to recent national inquiries into patient safety:

> *"We have got an advice and complaints procedure [set up in] the context of things like the North Stafford enquiry where the government is now expecting us, and rightly so, to be listening to things that our patients are telling us in that context*". Health professional, CCHP Staff workshop 1.1

This echoes calls to involve patients and members of the public in healthcare improvement in response to serious clinical and service failings in the UK and internationally (Ocloo and Matthews, 2016).

8.3.2 Ensuring the participation of all young people

Children's rights are about more than children and young people's right to have a say in matters that affect them. The CRC also recognises that children *"also have particular needs and vulnerabilities that require special protection beyond the rights to which adults are entitled"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.6). In the Y-SBNT study we were seeking to involve young people deemed to be particularly vulnerable:

> *"[The young people involved] need so much support [to participate] because they're pretty chaotic, have multiple problems."*
> Research team member E, Y-SBNT TMG focus group

This quotation does not suggest that these young people should not be involved, but rather highlights the need for a young person-centred and flexible participation in order to embed the involvement of these young people in the study. Indeed young people deemed

vulnerable are often in greater need *of "access to, and exercise of their rights"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.8) and may indeed have something unique to offer if supported to do so. This was certainly something which was expressed by some of the young people involved in the study:

> *"I think it's important to involve young people who have used drug and alcohol services as they can understand what it's like for others who are in the shoes that they've been in."* Y-SBNT young advisor A, contribution to project report

> *"Young people who have used drug and alcohol services will be able to reflect on their past use of services and give relevant feedback… I'm very much used to discussing my substance use history in a very negative light with no real benefit at the end but this project has helped me realise that a negative experience has made me wiser."* Y-SBNT young advisor B, contribution to project report

Potential tensions emerged in the CCHP workshops between the rights of young people using CAMHS to say if they are unhappy with their treatment and clinical judgements about best interest and vulnerability:

> *"We had this discussion in CAMHS the other day about young people phoning in and talking to somebody who wasn't their clinician about not being happy or something not [being] right in their [therapy] session and [the professionals'] concern was that they might not be happy because that's part of the therapy… or they weren't happy because they weren't happy [because of mental health]…It's not listening, is it? And how are [children] ever going to have effective therapy if they're never listened to?"* Health professional, CCHP Staff and YP workshop 1.4

This suggests the need for critical reflexivity and shared learning on the part of both the young person and the professional, as well as the need for a shift from expert to interpretive models of professional practice (Percy-Smith and Weil, 2003). The quotation also touches on issues of power in the therapeutic relationship and the idea of professional identity being based on 'the 'expert' professional who knows best.

In order to participate fully young people need not only to be respected as rights-holders but for there to *be "mutual esteem and solidarity, and a sense of shared purpose" (*Thomas, 2012, p.463). This includes understanding young people's perspectives but also clearly explaining what is and is not possible, as one of the young people involved in the project said at our first workshop:

> *"I don't think that [participation] is about just doing what [children] want but it's about listening [to us] and your listening resulting in some sort of change whether that be a physical thing or a change for that [young] person or a change for them in the way they feel about [the issue] and whether they felt like they've been listened to, even if you can't act on it".* Young person, CCHP YP workshop

For this young person participation was very clearly about respect and recognition but not necessarily change. The case studies also highlight the importance of structures and systems in providing different opportunities for young people to participate, both feedback and complaint mechanisms but also more proactive and collaborative forms of engaging

young people along with professionals in learning for change and joint decision-making processes.

8.4 Participation is not just about young people

The participation of young people in both case studies was seen as potentially including adults - either parents and carers or professionals - who may both enable and potentially constrain young people's participation (Cree *et al.*, 2002; Hood, *et al.*, 1996). In the CCHP the support of parents and carers played a key role in enabling some young people to participate:

> *"It's also about recognising that for some children we cannot exclude parents from some [participation activity] ...depending on the [children's] needs...So, we've got to keep that in mind also, that parents are involved in some way*."
> Health professional, CCHP staff and YP workshop 1.4

Members of a parent's group in a learning disability service also talked about how they saw their role in helping their child participate:

> *"Children can be misinterpreted. So the parents can say what their children are trying to say. Because I think sometimes you know what your children are saying without them actually saying the exact words".*
> Participant, CCHP parent focus group

This was about more than supporting recruitment and bringing young people to participation meetings or other activities. These particular parents saw their role as advocates and interpreters for their children but were also involved in participation activity in their own right, and this was felt to be important by both professionals and parents:

> *"It's no good just having the child's view or just the parent's view...because the professional is going to be dealing with both sides, possibly sometimes separately...So you need both opinions there".* Participant, CCHP parent focus group

> *"[Participation] has been good because...what I've found is finally my son has got heard, so now I am [also] being heard [as a member of a parents' group]".*
> Participant, CCHP parent focus group

But there was also awareness that, while for some children and young people using CCHP services support from parents or carers may be a key factor in making participation possible, for others it may silence or override their participation:

> *"Some young people will be supported by their parents in having a say, some might...be the complete opposite. [The role of parents in participation] is something we need to consider [in the development of a participation strategy] isn't it?"*
> Health professional, CCHP staff workshop 1.2

There was discussion in an early workshop about changing the focus of the work from 'children and young people's participation' to 'children, young people and families'. But given that the dominant model in health services is still one in which the *"consultation*

takes place between a health professional and the parent as a proxy for the child" (Redsell and Hastings, 2010, p.xiii) the group consensus was that it was important to keep the focus on young people's participation and ensure that parents and carers were not used as a proxy for young people's views:

> *"If you're getting feedback, make sure that you're speaking to the young person or the child, not automatically directing it at the parent or carer. Because that's really easy to do…and then you don't always get the right feedback."*
> Health professional, CCHP Staff and YP workshop 1.4

In the Y-SBNT study it was predominantly substance misuse services, rather than parents or carers, who enabled and facilitated young people's involvement in the study. Many of the Y-SBNT young advisors were living independently and not necessarily in contact with their families, so most of the young people who became involved in the study did so through services that were currently supporting them or had done so in the past:

> *"The young people who have become engaged have almost all done so because someone in a service has got what we're doing and has actively promoted it."*
> Research team member A, Y-SBNT TMG focus group

The perceptions of vulnerability and 'best interest' discussed in the preceding section were also said to impact on whether services, in their role as gatekeepers, supported young people to access opportunities for participation:

> *"You need to make [project workers] understand the importance of [participation]… it's [about] explaining to [project workers] why it's important…a lot of [project workers] are very protective over their clients if they feel that they're a little too vulnerable or, I hate that term, chaotic"*. Y-SBNT young advisor B, phone interview

The role these services played, and could potentially play, in young people's participation in future research studies is discussed further in Chapter 11. But the key point here is that young people's participation was in both case studies conceptualised as potentially involving significant adults in young people's lives.

8.5 Conclusions

This chapter considered how participation was conceptualised in the two case studies and what this means for the embedding of young people's participation in health services and research. This study found that participation can be conceptualised in two main dimensions: individual and strategic, focused on what young people are involved in, and individual and collective, focused on how young people are involved. In neither case study were there clearly delineated distinctions between individual, strategic or collective participation, and in practice young people involved in both case studies moved between levels and types of participation at different points. It was also important to be able to review and adapt pre-conceived conceptualisations and models of participation when these were challenged by the realities of participative practice.

Exploration of how participation was understood highlights the potential role of children's rights in informing the understanding and practice of participation, and potential conflicts between participation and protection rights. Children's rights and the CRC were central to young people's participation in the CCHP and the group with whom I worked developed a definition of participation which sought to move away from young people 'having their voices heard' to a more active participation which acknowledged the role of organisational culture in embedding participation. But this is not necessarily the case across the health sector or in health research where children's rights tend to be mentioned in passing rather than being seen as key to informing practice. The predominant culture in many health services is still one which does not translate the concept of participation into a transfer of power and choice. In both case studies participation tended to be conceptualised as a process determined and controlled by adults rather than a more collaborative and participatory practice. In the chapters which follow I will explore how these issues informed organisational culture, structures and systems in each case study, the role these played in enabling participative practice, and what this meant for young people.

9. Cultures of Participation

The preceding chapter considered how participation was conceptualised in my case studies. This chapter builds on this to explore the role of organisational culture in embedding participation, drawing on learning about the specific cultures of my two case studies as well as how wider cultures in health services, research and the public sector informed these organisational cultures.

9.1 Understanding culture

A culture of participation has been described as *"the ethos of an organisation, shared by all staff and service users, which demonstrates a commitment to participation"* (Wright *et al.*, 2006, p.12). The Hear by Right standards (Badham and Wade, 2008) suggest seven standards that contribute to a culture of participation: strategies, structures, systems, staff, skills and style of leadership, bound together by shared values. These understandings highlight the importance of a shared understanding of participation, as discussed in the previous chapter, in developing of a culture which supports the embedding of participation in practice:

> *"...organisations that are successful in involving children and young people are those that see participation as a wider concept, reaching beyond specific events to include a whole or overarching approach, leading to the development of participatory cultures" (*Kirby *et al.*, 2003, p.13).

In the CCHP participants talked about how they saw participation as both a process and a commitment to change, not just 'ticking a box'. People used journey metaphors to describe what they thought was needed to develop a culture of participation:

> *"While we don't always feel like we're moving forward, I think this whole initiative [development of the participation strategy] is designed to build on our success and learn from where we're not so successful and trying to move forward all the time"* Participation worker. CCHP staff and YP workshop 1.4

> *"We're beginning to shape the next direction and we're on the road and we're moving closer and closer to where we want to be...I feel like we're all very clear about where we need to go".* Health professional, CCHP staff and YP workshop 1.4

Embedding a culture of participation was defined as collaboratively agreeing a direction of travel and a shared vision, but also building on work that has already done. Culture is not fixed or static, and can create barriers to children and young people's participation as well as providing opportunities for the development of more participative ways of working (Wright *et al.*, 2006). Embedding a culture of participation in a large and complex organisation like the CCHP was not straightforward, as it needed to incorporate both the culture of the organisation as a whole and the cultures of individual services, areas or professional groups and the wider NHS. Participation was more embedded in some of these elements than others:

> *"I think it's far more embedded within the culture of physiotherapy now that we've gone through this process [piloting the participation strategy]. I would say that has helped us as a service to embed it more within our culture of working."*
> Health professional, CCHP staff and YP emerging findings meeting

The physiotherapy services had a chance to think about what participation meant for them and how it could be embedded in their services in the three workshops I facilitated while they were piloting the strategy and framework, as well as through support from Barnardo's in between and after these workshops. Their team leader had also been involved in the strategy development groups which preceded the workshops, so already had a good understanding of participation and was committed to developing practice. The challenge was whether and how such a process could be replicated for other CCHP services and the organisation as a whole:

> *"[We] talked about…how the strategy should support/promote an organisational culture where participation is actively invited by staff (hence need for strategy to drive this) rather than just promoting children's rights to participation".*
> Research journal 15/1/14, notes on CCHP core group meeting

Embedding participation could mean that it happens as a matter of course rather than people having to consciously remember and 'invite' young people to participate, but the sense at this stage with CCHP was that a lot of work still needed to be done to develop a culture in which this could happen as part of everyday practice. In addition to the importance of the strategy to embedding an organisational culture of participation this excerpt raises an interesting question in relation to children's rights first touched on in the previous chapter: should the focus be on creating opportunities for children and young people's participation rather than raising awareness of rights which they may not have clear opportunities to exercise? Involving young people in making such decisions was a key part of the way in which we worked together during the CCHP workshops, as discussed in the section below, but in the CCHP children's rights were an important part of understanding the culture of participation. .

Considering how culture was understood in the Y-SBNT study highlighted a fundamental difference between the two case studies, one was a large organisation with a shared history and (recommissioning allowing) a shared future, the other a time-limited research project with a team based in a number of different institutions across the country. However both case studies had a 'culture' in the sense of a set of shared values that influenced practice. In the case of the Y-SBNT study this centred on a shared commitment to young people's participation in the research process. From the outset young people's participation was seen as both a process in its own right and part of other, larger systems and processes, in this case the whole Y-SBNT study and the wider context of public involvement in health research:

> *"...embedding [participation] means [young people] are there and part of the [research] team, and this isn't just about young people I'm talking about all PPI in research. It's somebody or people who are there right the way through the entire journey".* Research team member F, Y-SBNT TMG focus group

Although the journey metaphor occurs here as in CCHP, generally young people's participation in the study was articulated in terms of the 'research process' rather than culture. But other members of the team described participation as something slightly separate from this process:

> *"[young people's involvement in] this project has been another thing to think about whereas naively I hoped it would be something that would help me with the whole [research] process".* Research team member B, Y-SBNT TMG focus group

The above quotation suggests that meaningful, effective and sustainable participation needs to have clear benefits for the organisation, service or project as well as young people in order to be embedded. It illustrates how a shared vision of participation (young people being part of the research team and *"there right the way through the entire journey"* as the first quotation above) was not in practice an integral part of the culture of the Y-SBNT study. Young people's participation was at times, as above, *"another thing to think about"* rather than being seen as an embedded and integral part of the research process. But I would argue that participation can be embedded without being integrated, i.e. as a parallel process, and may indeed have some independence by doing so. This study found that there needed to be a shared commitment to children's participation across the organisation and/or team but this did not necessarily mean that young people, or the adults supporting their participation, would need or indeed want to be part of every aspect of decision-making. Having a degree of independence may also make it easier for young people and participation professionals to be 'critical friends' as discussed further in 10.1.3 and Chapter 11. The quotation above also articulates a frustration, which I shared, with the amount of time which was taken up trying to get and keep young advisors involved in the study, rather than focusing on how they could be involved. Although we did end up with a model of participation which worked for the research process and the young people involved, this happened towards the end of the study. In the chapters which follow I consider whether young people's participation would have been more 'embedded' in the research process and culture if this had happened earlier, for example would young people have been more involved in decisions about how and when they were involved? But first I will consider what it means to establish an effective culture of participation (Kirby *et al.*, 2003).

9.2 Establishing a culture of participation

Understanding the culture and processes of participation was a key element of the learning process in both case studies. Alongside the idea of a rights-based understanding and culture of participation within and across CCHP services was an emphasis on the importance of commitment to participation as a collaborative process, and developing a culture of learning with and from young people. For example the process of developing the posters and other materials (see Figure 10 below) highlighted how building a culture of participation is something which could, and should, include young people:

> *"[W]e made a story board, t-shirt and poster designed to promote the strategy. Each was produced by a mixed team of CCHP staff and YP…I think that having this practical aspect to our meeting really broke down barriers between staff and YP and I am in no doubt that the end result wouldn't have been nearly as good if the adults and YP had worked in separate teams".*
> Young person, writing in newsletter from CCHP workshop 1.4

Figure 10: T-shirt and poster developed by staff and YP in workshop 1.4

This creativity and collaborative working happened at a point where I stepped back, after the participation manager suggested that Barnardo's participation staff and young people plan and lead a session on promoting the strategy to staff and young people. This was partly to reengage people after a two-month gap between workshops, as we had needed to wait for half term so that young people could attend. But my discussions with the participation manager also identified a potential problem around my role in the organisation and facilitation of the workshops:

> *"…[There is a potential issue] around ownership of the project….[participation manager] thinks that my facilitating and organising the [workshop] sessions may have led to some people taking a step back, but on the other hand nobody has been volunteering [in response to my requests to help plan, deliver or report on the workshops] because they're all really busy! Is there also an issue here re: the fact that this is also my PhD research so to some degree the timing and agenda has been led by that?".* Research journal, 13/02/14, prior to workshop 1.4

I tried from the outset to frame the CCHP workshops as a collaborative process of shared learning, but the above excerpt from my journal highlights another aspect of understanding culture: the culture within the group with whom I was working. This was partly because people were busy but also because there was an organisational and wider health service culture in that both staff and young people attending the first cycle of workshops appeared to expect a fairly traditional set-up in which I planned and led the meetings. Furthermore this was a process which I had initiated for my PhD rather than something that emerged organically from within the organisation, and therefore the timetable and methodology were to some extent led by academic requirements. As discussed in 4.2 there are inherent tensions between taking a participative research approach and the requirements of postdoctoral study (Herr and Anderson, 2015). But I sought to acknowledge and address these tensions throughout the process, and to share responsibility wherever possible. I used participative methods throughout the workshops and emphasised that these events were only part of the process, and that the real work of embedding participation in the CCHP was what happened in between. In terms of the action research cycle the workshops were a chance for people to plan for change, reflect on processes and consequences and then replan (Kemmis and McTaggart, 2000). The part of the cycle which involved acting and observing the process and consequences of the change (Kemmis and McTaggart, 2000) happened when people went back to their services and tried to implement actions agreed in the workshops. At the end of each workshop we collaboratively agreed the agenda for the next one. The structure of overall process was also developed in collaboration with the group, who agreed at the end of the third strategy development workshop, which we had planned would be the last one, that they wanted another:

> *"[A]lthough I was [still] facilitating, it really did feel like the group is working together collaboratively really well and owning the strategy - there was a lot of talk of what 'we' need to do. Towards the end I heard a small group of staff and a couple of young people making plans to meet and do some work on the strategy together in January, which is fantastic! Feels like it's taking on a life of its own…Although we'd planned three workshops people wanted to meet up again, so we'll fix a date for this during Feb half term".* Research journal, 05/12/13, reflections on workshop 1.3.

At this stage, although there were still expectations of me as a facilitator, I felt that a sense of shared ownership was becoming part of the culture of the strategy development project. But developing a culture of participation which incorporated strategic as well as individual-level participation across the wider organisation was less straightforward:

> *"[H]ow do we engage? Because even the engagement of [some services in] this process [the participation strategy workshops] is a struggle, but the gap in understanding of participation across the partnership is still big, although the range has narrowed from where it was 4 years ago. I think still I would say that the majority view [of children's participation] tends to be about [children] getting involved in services, it's about access to services as opposed to your views changing services and your care".* Participation worker, CCHP staff and YP workshop 1.2

The quotation above reflects the challenges of developing an organisation-wide culture of participation when *"the predominant culture in most health and welfare agencies [still] emphasises the vulnerability [and perceived competence] of young people"* (McNeish, 1999, p.194). Integrating participative working into practice was key to embedding a culture of participation in the CCHP. The group sought to address by continuing the participative process through which the strategy and framework had been developed, rather than imposing something which could be seen as 'top-down':

> *"[I]t's really important for there to be a stage before the dissemination stage, which is what [another health professional] was just saying about [the participation strategy] not being one of those things that just comes to you and you take minimal notice of it because you don't feel you've got time and you weren't consulted and you're not engaged".* Health professional, CCHP staff and YP workshop 1.2

Another way to embed a culture of participation was for those who had been involved in the development of the participation strategy to share their experience:

> *"How do we ensure that everyone who works in CCHP and uses its services believes that participation is important?…they'll think it's important if they really understand or believe that it improves the service they can deliver… we've done this work [piloting strategy and framework in our services] and we should then share it with our colleagues and other professionals, other therapists who work in a similar way, and maybe…they might be interested to use the things that we've developed, they might have other ideas…[there's] no point just telling people they've got to do it. It just won't work".* Health professional, CCHP staff workshop 2.3

This highlights the importance of developing a shared vision and commitment to participation, as there can be variation in cultures of participation within organisations (in the case of CCHP) and within a project team (in the Y-SBNT study).

Young people's participation was part of the Y-SBNT study from the outset, and there was a commitment at least in principle to support that participation all the way through the study. However in the first year or so the research team and TSC were focused on young people's involvement in the first stage of the study: the adaptation of the original adult intervention for young people. Plans for participation in later stages were limited in the proposal to naming the stages at which young people could potentially be involved:

> *"I thought that there would be this great big involvement of the young people in the development of the intervention to begin with".*
> Research team member F, Y-SBNT TMG focus group

People had been recruited to the research team to lead on or contribute to different aspects of the study because of their expertise and prior experience. But on the whole this was a team with varied prior experience of public involvement, particularly involving young people:

> *"I'm not sure I had any definite expectations [of YP's involvement in the study] because it is all fairly new to me. I mean I suppose I've spent my career in and out of research in this area [substance misuse] without public participation".*
> TSC member B, Y-SBNT focus group

It is not always necessary for young people to be fully involved in all stages of research, and it can be more appropriate to create *"pockets of participation"* (Franks, 2011, p.15), in which the appropriate level of involvement is determined by the circumstances of the young people involved (Kirby *et al.*, 2003). But in order to embed participation in the Y-SBNT study it was necessary to consider, in consultation with young people wherever possible, if and how they could be involved throughout the study:

> *"I guess I... [viewed] this as an opportunity to engage young people in a feasibility trial and all the bits of that pretty much in equal measure. So even though there may be different focuses at different times...my expectation was that we would do our best to engage and embed that engagement all the way through the whole trial and all the different aspects of it".*
> Research team member A, Y-SBNT TMG focus group

While young people's participation was an area with which I was certainly familiar, and the reason I was asked to join the team, I had limited prior experience of supporting the participation of young people affected by substance misuse. My prior experience of health research had also been as an external adviser rather than being a member of a clinical trial team, and I have a social rather than clinical research background. This meant that there was a lot of shared learning on all sides, for all these reasons and also because a substantial amount of the time allocated to participation was spent working out how best to recruit and retain young advisors to the study. As outlined in the previous chapter in the CCHP we started with conceptualising participation based on established practice and an existing culture, and in the Y-SBNT study developing a culture of participation was something that happened later on, when we had gained experience of supporting the participation of the

particular group of young people who we wanted to involve. The process by which we got there is explored in the chapters which follow, but the learning from young people's participation in the Y-SBNT study challenged aspects of the culture of participation in health research, not least the efficacy of the YPAG as the standard model for involving young people. This brings me back to the idea of a culture of participation and research being both a process and a journey, echoing Wright *et al.*'s (2006) suggestion that *"culture is not static but something that can change over time"* (p.6) and also, in the case of an organisation like CCHP, something that can change across different elements of an organisation. These processes and journeys were central to this study and to developing an understanding of what happens between the rhetoric of participation and the reality.

9.3 The wider context

Any consideration of organisational culture in health services and research needs to consider how 'culture' applies in a wider context. The Y-SBNT study was informed by a wider culture of public involvement in health research, as well as having a research team based in different academic institutions across the country. The CCHP was part of a much larger NHS. Developing shared understandings and a shared culture of participation was not a straightforward thing to do in a complex organisation which included *"a vast range of health professionals from various different disciplines and also different [geographical] areas"* (Health professional. Staff and YP workshop 1.4):

> *"This [participation] strategy…has to feel like it's broadly relevant to all these different services…That's not going to be easy, but because the [CCH] partnership is so diverse, how you term that in a way that feels like you're also backing up the need for consistency…taking into account local need as well? Maybe physio[therapy] and OT [occupational therapy] and speech and language is easier because at least you've got one professional lead, but then it becomes quite difficult for other services… [Who is] responsible for coordinating the paediatrician's plan for participation, and how does that fit with the other child health colleagues in [allied health professional] services? It's a tricky one".* Participation worker, Staff workshop 1.2

Following on from the discussion about provision and protection rights and understandings of childhood in the previous chapter, there was an interesting discussion with the CCHP physiotherapy team when they were piloting the implementation of the participation strategy on whether they could re-frame the assessment language of 'problems' and 'concerns' into sometime more positive:

> *"When you've done your assessment…it's really important for us to have a problem list because that relates to the areas that treatment would be centring on and it's important that staff aren't airy fairy and actually do focus on what the true problems are".* Health professional, Staff workshop 2.2

Although this discussion was resolved to some degree by adding a box for 'child's goals, concerns and expectations' on an initial assessment form, it illustrates some of the cultural tensions between medical models of treatment and what might the participant above described as the more *"airy-fairy"* language of participation. In the final workshop with the physiotherapy team there was a discussion about some of the challenges the team had faced in trying to embed cultural change, in relation to both the time it takes and the practical challenges of getting people together to work across teams and areas:

> Louca-Mai*: "So what have we learned about trying to embed participation in practice?"*
>
> Health professional: *"That it's hard…for cultural reasons because it's very time-consuming and because it is change and people take a long time to adapt to change…those [practitioners] we need to engage with are the hardest to engage with, and that's what makes it more difficult, and because it's a CCHP-wide project, it takes more time to get us all together than it would if we were just in teams".*
> CCHP staff workshop 2.3

Although embedding cultural change across the organisation was challenging, the CCHP had the advantage of an established organisational culture of participation from the outset: with an NHS Trust and voluntary sector organisation as contract partners and young people and families involved in developing the original service model (Roberts *et al.*, 2008). Thus my work with them was essentially about building on and embedding this participative culture. By contrast the Y-SBNT study was a new project with a team based across various institutions and geographical locations and with varied prior experience of research with young people or public involvement in research. So the starting point for my work in the Y-SBNT study was trying to establish a culture of participation within the wider framework of public involvement in health research. There was also a disconnect between the intention to involve young people in the study from the outset, and the reality of trying to engage young people who were much less likely to participate in research or other participation activity:

> *"I think we may be under pressure [now, when planned approach to participation appears not to be working that well] because in research…you have to say what you're going to do [at the proposal-writing stage] and you come with that framework in your mind but as we found it's more useful for [the young people involved] to have a combination of various forms of [participation]…we're expecting people to somehow come in and engage with us and maybe they take one look at it and think 'I'm not interested in this', or they're interested for a bit but it takes time".*
> Research team member B, Y-SBNT TMG focus group

There is a network of established YPAGs in England (e.g. CRN: Mental Health, 2016; DECIPHer, 2016; GenerationR, 2016) and it is possible for health researchers in England to take research ideas and proposals to these groups to get young people's input into their research. But, while these groups generally have a good understanding of clinical research,

in the Y-SBNT study we needed input from young people with specific experience of substance misuse services, in a sector where there is not a strong culture of participation:

> *"[Charity] have found that generally they need to work harder to get managers on board and get services involved with any participation activity, not just this project, as it's not part of the culture of many [substance misuse] services".*
> Research journal. Notes of 10/14 meeting with YP's participation lead from national charity involved in early recruitment

The culture and structures inherent in health research, compounded by the lack of established participation in many substance misuse services, meant that the Y-SBNT study started with a 'traditional' model of young people's participation – the YPAG - and we then learnt the hard way that this did not work for the young people we wished to involve:

> *"I probably was very naive about young people's involvement [at the start of the study] and I would have looked at all the models of PPI where you've got [young people's] advisory groups and thought we could have done something similar with young people, but given all our experience [during the Y-SBNT study] that was a very naive view I think".*
> Research team member C, Y-SBNT TMG focus group

For participation to work best in a study like Y-SBNT there was felt to be a need for cultural change within the wider system:

> *""This is not just about embedding in a particular project [participation] needs to be embedded in the wider systems which are supporting that project…as a routine thing that clinical services are doing as part of everyday [practice]…in the way that the local commissioning structure needs to work… in research funding structures…perhaps embedding is a whole system type of thing, we can't always expect it to function clearly in a particular project if it's not going to be able to function when you have to have contact with those other bits of the system".*
> Research team member A, Y-SBNT TMG focus group

Wider cultures can both inform and be informed by participation in individual projects and services, and feeding back the lessons from involving young people in the study was seen as important because:

> *"…the government and the Department of Health talk glibly about public participation. I think they need to know just how difficult it is."*
> TSC member B, Y-SBNT focus group

Embedding young people's participation in health research requires more reflection and sharing of learning on the challenges and realities of participation.

As the Y-SBNT study started with an established model for involving young people in research, my work with the CCHP also began by considering existing models of participation:

> *"We…looked at the various participation tools and models people had agreed to consider after the first workshop, which were stuck on the walls around the room. These included Hear by Right, Young People Friendly and others …We discussed whether and how are these were useful and relevant (or not) to embedding children's participation in the CCHP".* Notes from CCHP staff workshop 1.2

After agreeing a shared understanding of participation we mapped participation activity across the organisation (Appendix 6) and reviewed the use of existing tools and resources:

> *"...there are things around Young People Friendly which there are lots of offshoots from...and IAPT...which is Improved Access to Psychological Therapies, and we won an award for that...and then there is the Picker Institute [survey of patient experience] which is going to be coming online for child health imminently and that's an annual look at what people think [about services]. So there is...a lot going on. It is how it connects and relates to each other that is my biggest concern, so it is not to say that nothing exists, but it often exists in isolation of something else and it is not linked".* Participation worker, Staff workshop 1.1

This exercise illustrated the complexity of participation activity and cultures within the CCHP, as well as the lack of links between the various externally-generated participation tools, resources and initiatives. There was generally a sense of wanting to be connected to other programmes and projects but also an acknowledgement of a need for something new which fitted with existing work. For example, Young People Friendly (YPF) is a Bristol-based accreditation programme for healthcare providers used by CCHP (4YP, 2014). But participation is only one element of YPF so the group felt that a strategy and framework were needed to expand on and link into that. Participants also talked about the Hear by Right standards (NYA, 2010) and, while acknowledging that many of the principles applied to the CCHP's participation work, people said they found the process of attempting to complete these standards *"turgid"* and *"overly onerous"*. The starting point suggested by the participation manager for our work, and agreed by the rest of the group, was Wright *et al.*'s (2006) whole systems approach, which also informed the theoretical framework for this study (see 2.5). It was also felt important to link into national initiatives promoting a wider culture of participation within the NHS:

> *"[NHS Change Day] is about trying to get a sense that everybody's got a stake in the NHS and how we're going to make this a good service in the future... it's trying to get a sense we're all in this together and we've all got a role to play and it's not just government or your boss... [making a Change Day pledge] is a way of saying that [the NHS] is for everyone, not just for the people who work there or the people who happen to be in the service".* Participation worker, Staff and YP workshop 1.4

In addition to the need for a culture of participation to be *"shared and understood by managers, practitioners, children and young people"* (Wright *et al.2006,* p.6), commissioners, regulatory bodies and the wider sector also had an important role in embedding participation in the CCHP, for example: *"Ofsted want to see clearly the voice of the child [during inspections]"*. (Participation worker. Staff workshop 2.2). External bodies can thus provide both carrots and sticks to encourage participative practice, through encouraging and promoting good work as in NHS Change Day or through demanding evidence of participation when commissioning or inspecting services.

Much of the debate on public involvement in research is about how that involvement benefits research and those involved, but ultimately public involvement in health research should also benefit users of services and the wider public through services, treatment and interventions which better meet their needs (Gibson, Britten and Lynch, 2012). The purpose of Y-SBNT study was ultimately to pilot an intervention in services, so it was therefore about young people's participation in service development as well as in research. However there were questions about how much young people's participation in a study such as this could ultimately influence how services are commissioned and delivered, particularly in a climate of reduced budgets and frequent restructures, and therefore the extent to which such involvement could be meaningful:

> *"I suppose a fundamental question for me about public involvement, in the current climate where people are making difficult decisions about services and research, is how much attention they really pay to it. I mean we can do all the work we want and involve young people and where is it getting? Are they really being heard? We are all enthusiastic we want to involve young people in the project, they develop and have a good time – but is it having an influence on what commissioners decide when they decide which services should be provided for young people? I doubt it".*
> Research team member B, Y-SBNT TMG focus group

An alternative viewpoint was that in a climate in which resources are scarce, young people's involvement in the development of an intervention could be an advantage:

> *"I think many commissioners are actually quite sensitive to these issues...if you can show that [an intervention] is actually rooted in young people's experiences and they've been involved in developing how best to deliver it that would be attractive to commissioners, that would be a plus! How it has that sort of mark on it is the question – and that's why I think a film on the side of the final product [intervention manual] would be a really good thing".*
> Research team member E, Y-SBNT TMG focus group

This suggests that involving young people in the development of an intervention or service could better make the case for its relevance to the target group, but also perhaps that a higher level commitment to participation at policy level means that commissioners expect it to be included in commissioning processes.

But although wider cultures and external influences to some degree encouraged and supported a culture of participation in both case studies, the aim of meaningful, sustained participation was also challenged by external events which made it harder to embed a culture of participation. In the Y-SBNT study wider cultural influences included the challenges of engaging young people in participation in the substance misuse sector as discussed above, and frequent changes to the services and staff with whom we were working due to re- or decommissioning and restructures. Procurement and recommissioning processes, along with the increasing break-up and privatisation of NHS services, present significant barriers to embedding a culture of participation in health services. There are no guarantees that the CCHP will stay in its current form after

recommissioning, or that participation will continue to be as central as it has been to the culture of the organisation and all the services within it. But as the participation manager said in an email to me, this change, while disruptive, may yet provide new opportunities:

> *"Change of this nature takes up huge resources of money and time causing inevitable distraction and compromises. Good participation is based on relationships and huge changes to services [will] change [these] relationships, but [change] can also bring new opportunities for better models of care and service delivery"* (Roberts, 2016).

When I started working with the CCHP there was an organisational culture of participation underpinned by well-established working relationships, but this was subsequently threatened by recommissioning and potential restructuring. The Y-SBNT study was a time-limited project with a disparate team, so cultural change in this instance was more about whether and how the lessons learnt will influence the wider culture of young people's involvement in health research.

9.4 Conclusions

This chapter considered how the understandings of participation explored in the previous chapter inform the cultures which underpin participative practice. A culture of participation is both a process and a journey, something which needs to happen as a matter of course rather than something which people have to consciously remember to do, or invite young people to do. It can be based on established practice and an existing culture (as in the CCHP) or be something which emerges through shared experience (as in the Y-SBNT study), or indeed a combination of both. Establishing a culture of participation requires building on existing models, tools and quality criteria by critically reflecting on their relevance and adapting them as necessary. This is not about creating something new but creating more opportunities for critical reflection and shared learning within and between organisations and projects.

The boundaries of a culture of participation are less straightforward than the literature appears to suggest; it is also something that can vary considerably within and between organisations in health services and health research. It can also be embedded without being integrated, and there are benefits to it being a parallel process in which young people and those supporting them retain the independence to be 'critical friends'. Furthermore a culture of participation, and the factors which shape it, go beyond the organisation or project itself to include the systems and structures within which they operate (in this case the wider NHS and the NIHR and associated bodies). Participation in health services and research tends to be driven by a public involvement and engagement agenda rather than discourses of children's rights or participatory practice. To order to be embedded a commitment to participation needed to be shared and understood by

managers, practitioners and young people, but also by commissioners, regulators and other external bodies.

A culture of participation is a set of shared values that inform practice. Ensuring that participation is meaningful, effective and sustained requires appropriate and adequately-resourced mechanisms to support a cultural commitment to participation (Wright *et al.*, 2006). So I now turn my attention to the structures and systems which can enable the rhetoric of participation to become reality.

10. Frameworks for participation

In Chapters 8 and 9 I considered how participation was understood in my case studies, and what it meant to embed that understanding within the culture of a health service or research study. This chapter considers the role of responsibility, leadership and planning for participation in creating frameworks for participative practice.

> *"[We need] strong principles, strong values, strong standards and strong sense of unity and direction and priorities…and a strong structure, that is so critical, the structure needs to be strong".* Participation worker, CCHP staff workshop 1.1

In Chapter 11 I go on to explore the role culture, structures and systems played in embedding participative practice.

10.1 Responsibility and leadership

10.1.1 Participation leadership

In the CCHP managers and professional leads were seen as key to embedding participation:

> *"[Participation] has to be engineered to start with because left to its own devices you will get a handful of people…that are going to be able to do something with support…with the enormous expectations that are now on people's working and personal schedules, you are going to need [management] to say 'this has to for a period of time be a priority' and then when we review it work out how it is going to be sustained. Because there is always somebody else that says 'I am more important, this is more important' and if [participation] isn't one of those things that's being said is important then it will just be drowned out by other targets and commissioners".* Participation worker, CCHP staff workshop 1.2

But engineering the embedding of participation was far from straightforward in CCHP as there were both geographical and professional management structures, as well as being part of a larger NHS Trust and the wider NHS:

> *"[There are]…service managers…area managers…senior managers…area coordinators…clinical governance…you just get lost in managers."*
> Participation worker, CCHP staff workshop 1.2

Decision-making processes and responsibilities were often unclear, certainly to me as an outsider. The challenge in this instance was how to get management support to drive participation forward amongst completing agendas and changing priorities.

The Y-SBNT study was a relatively small, time-limited research study rather than a complex organisation but nonetheless management support for participation was also not straightforward, although for different reasons than the CCHP. As the research team were based in a number of different institutions management of the study was generally about project management rather than line management (only the two research fellows were line

managed by another member of the study team). The other public involvement lead and I were included in the study team with responsibility for:

> *"...implementation of Patient and Public Involvement throughout the study and to lead the consultation [participation] work...Recruit and organise meetings with young people and family members, develop methods for the consultation [participation] process in collaboration with other co-investigators and produce reports of the results of this work to feed into the final intervention manual".* (Y-SBNT proposal. Copello *et al.*, 2012, p.17).

Participation plans were developed and reviewed in collaboration with the principal investigator, TMG and TSC:

> *"The TSC said that PPI was seen as key strand of study and they felt that it was much more in-depth than PPI normally is".* Research journal, 03/06/14

Participation was supported by the funding body in that they agreed to support both our initial plans for involving young people in the study and raised no objections to details of changed plans in project monitoring reports as the study progressed, but there was no active engagement in planning or delivering participation. Out work was also informed by high level leadership from NIHR and guidance from INVOLVE, the NIHR advisory body for public involvement. But the day-to-day management and the delivery of participation was my responsibility, in collaboration with the other public involvement lead. Therefore participation leadership was less about top-down management support for participation and more about leadership and responsibility on the part of the participation leads. I am aware that this is a point at which my roles in the two case studies come to the fore: in CCHP I was the external facilitator for a collaborative learning process, whereas in Y-SBNT study I was an insider, a participant researcher. I led the work on young people's involvement in the study and sat on the TMG, so I was part of the process as well as researching it for this PhD. I was employed on the study as a freelance consultant so, as well as being at a geographical distance from the rest of the research team, I was also responsible for day-to-day management of my own work. This had the advantage of allowing my fellow public involvement lead and I a fairly free rein to take young people's involvement in the study in the direction which worked best for the young people we wanted to involve, but it also meant feeling that at times we had to defend and champion participation to the rest of the team:

> *"[The other public involvement lead and I get] a lot of autonomy and at times acknowledgement of how hard we have worked [to try to get and keep young people involved in the study] - but at the same time [the TMG] talked about the significant cost of PPI...for relatively low returns...and YP's involvement in the project being 'scrappy' (to be fair this is true but not for want of trying!)."*
> Research journal, 12/02/15

While I certainly worked hard to address resistance to change and maintain participation as a priority the above quotation illustrates how the management role of supporting and encouraging participation practitioners (Wright *et al.*, 2006) can at times be difficult in a research such as this. The peer support from my fellow public involvement lead was invaluable but support from others in the team was equivocal, especially when things did not go as planned. The issues of peer support and developing practice for public involvement leads working with young people is something that has come up in other work I've done (Brady, 2013) as well as in the workshop I organised as part of my critical inquiry process (5.1.1). When discussing the pros and cons of the professionalisation of participation (Cairns, 2006; Cornwall, 2008) there is a need to consider how participation workers are supported when they are not part of a wider participation team or organisation. Furthermore, given that the success or otherwise of young people's participation in the study was ultimately my responsibility and something I was being paid to do, it is important to acknowledge that I had a strong vested interest in young people's participation being successfully embedded in the Y-SBNT study. This is not a study in which I sought to have an uncritical positivist objectivity, and this position gave me unique 'insider' insights that I would not otherwise have gained, but nonetheless it is something I considered carefully in my analysis and in writing this thesis and will discuss further in Chapter 12.

10.1.2 Participation in frontline practice

Both case studies explored the idea that organisational change needs to happen *"at the grassroots, with staff who engage with young people on a…regular basis"* as well as at senior management level (Kirby *et al.*,2003, p.57). So although the day-to-day management and practice of participation in the Y-SBNT was led by me and the other public involvement lead, we worked closely with the principal investigator and other members of research team. Our original plan had been for young advisors to have fairly frequent contact with the whole research team through their attendance at YPAG meetings, in which our role as public involvement leads would be principally to organise, help prepare materials and facilitate dialogue between the researchers and young people, with the agenda and content coming from the research team. In reality the more flexible, young people-centred model discussed later in this chapter meant that many the young advisors spent a lot of their time with me or the other public involvement lead and met other members of the team only infrequently. But we still tried to get members of the research team involved wherever possible and set out this intention clearly in plans for young people's involvement in the study:

> *"Louca-Mai and [other public involvement lead]'s role is to recruit young people and support their involvement in the study, but the content (what YP are consulted on and involved in) will be driven by the project team – led by [principal investigator and study coordinator] initially and then other team members as the study progresses. Louca-Mai and [other public involvement lead] will work with team members to plan meetings and activities which are relevant and accessible to YP, led by study priorities and timelines".* Y-SBNT PPI plan, v2 30/10/13

In practice timing and geography made arranging meetings with young people and members of the research team problematic, especially when we were meeting young people individually or they only knew their availability at short notice. This meant that some of young people reported feeling slightly at a remove from the wider team and their fellow young advisors:

> *"The individual model, while it's worked very well in some ways, I wonder because [young person] has said to us it would be great to meet the more of the [research] team and other young people, and we've not been able to get to a stage where we've been able to do that".*
> Research team member A, Y-SBNT TMG focus group

For many of the research team young people's participation was therefore something they read about in bulletins or heard about in meetings, rather than something which they experienced directly. The need for both management support and shared responsibility were acknowledged in the revised model for young people's involvement proposed at the end of the chapter I co-authored on young people's involvement for the final report on the Y-SBNT study:

> *"The main role of the public involvement lead(s) in this model would be to plan involvement activity, facilitate links between young people and researchers through the services, and evaluate this involvement…All members of the research team would ideally also be allocated time to feed into, and plan for, public involvement (particularly those who are, unlike the public involvement leads, directly involved in the study on a day-to-day basis). Management support is also essential to embedding young people's involvement in the study rather than it being seen as an 'add-on'".*
> (Watson *et al*., 2017, p.113)

The intention was to frame young people's participation in the study as something to which all members of the research team would contribute. This was partially achieved when we managed to get groups of young advisors together for meetings: members of the research team then planned and delivered sessions, as well as being able to report back to the TMG and TSC on how the resulting input from young advisors had informed the study. The challenging period was when our focus was on recruiting and retaining young people, and when a lot of the work with young advisors was individual or one-off meetings. However the TMG discussions during this period were nonetheless instrumental in informing the model for involving young people which emerged from the study.

In the CCHP those who volunteered to get involved in the workshops were already committed to young people's participation in some form:

> *"[W]e have come to be part of this group because [participation] is what we do. That is the point of the partnership, this participation, and it is vital that we are involved and have some role in developing the strategy".* Participation professional, CCHP staff workshop 1.1

> *"I think we have always done it [participation in our service], we just haven't formalised it…And that is why I wanted to be part of the group, just to make sure it is completely embedded".* Health professional, CCHP staff workshop 1.1

But embedding cultural change across the wider organisation required making it part of everyday practice and not just 'preaching to the converted':

> *"[P]eople go 'I haven't got the time, I can't be doing that, someone else will have to do it' but I feel that is the only way that [participation] will really filter in properly is if it really is just embedded in what we do".* Health professional, CCHP staff workshop 1.1

The participation strategy was seen as a key way to embed participation in everyday practice, but there was awareness that this needed to be something in which everyone in the organisation felt they had a stake:

> *"[T]hat is a challenge, isn't it really, to get people really involved and motivated and feel like [the participation strategy] belongs to them, because sometimes these things happen, it doesn't really feel like it belongs to the people that are [most] needing to do it".* Health professional. CCHP staff workshop 1.2

So although developing a shared commitment is important, this needed to be balanced with leadership which sought to engage those less involved and motivated towards participation. Such leadership could be through management support and, as discussed below, through participation staff and 'champions'.

10.1.3 Expertise and champions

The successful implementation of participation is often said to require the identification or appointment of specific members of staff "*dedicated to the development of participation*" (Wright *et al.*, p.24) such as participation workers. Alongside the importance of leadership and shared responsibility both case studies identified the need for specific expertise, skills and champions as crucial to the effective embedding of participation. Barnardo's role in the CCHP was to support and develop young people's participation and provide expertise:

> *"I am part of the Barnardo's HYPE team…we try and involve children, young people and parents as much as possible in work with any of the Community Health Services. We have a couple of young peoples' groups, we also speak to families to involve them in evaluations of services, and a lot of pilot studies. [We support children's participation in CCHP staff] recruitment and we do participation training".* Participation worker, CCHP staff workshop 1.1

The partnership aspect, with Barnardo's and the NHS Trust jointly contracted to form the CCHP, was seen as particularly important:

> *"It's such a unique model…what the [CCH] Partnership has and what Barnardo's have and what that brings together is so unique. I think that you can't underestimate*

what those two sides bring together to actually deliver one approach".
Health professional, CCHP staff and YP emerging findings meeting

The expertise and quasi-independent role of Barnardo's in the partnership was seen as crucial to its success in involving young people:

" [H]aving Barnardo's... [as] a voluntary sector pusher, a facilitator, alongside the services is absolutely essential. I don't think [clinical services would] have the time and energy to even participate in participation, let alone to drive lead, support, engage with the young people. I think it has been superb having Barnardo's HYPE team and...I struggle to see how you could do it differently unless you put an awful lot of resource into a statutory service to just have a participation unit, and I can't see in the current framework and funding that actually happening".
Health professional, CCHP staff and YP emerging findings meeting

As Barnardo's were not responsible for delivering clinical services they were perceived as being in a more neutral role. This enabled them to be a 'critical friend', as well as championing participation and taking the lead in developing practice and evaluating participation. But at the same time this did raise issues about how to make participation 'everyone's business' rather than something Barnardo's did for the CCHP.

There was an acknowledged need for CCHP staff at both senior and front line practitioner levels to become champions for a number of reasons. Firstly to represent the views of other practitioners:

"Part of the reason that I wanted to be here at this...[workshop] today is because I know quite a lot of people that aren't here...people within the Partnership whose voice and views I would quite like to represent as well ...lots of things that have been said to me over the years that I would really like to make sure are put out there."
Health professional, CCHP staff workshop 1.1

Secondly, participants talked about the need for champions to cascade participation and drive the embedding of participation in individual services and areas:

"In [type of service] we get a representative from each area and form a little subgroup, and then those people are responsible for...cascading information down to the team, so it means that each area has some sort of participation [input] into it....it works really well". Health professional, CCHP staff workshop 1.2

"[I]f we're going to have an action plan for each particular service then somebody [needs to be] responsible for driving that action plan forward and then maybe come to a group to say, 'right, this is how we're getting on with the action plan'."
Health professional, CCHP staff workshop 1.2

Thirdly, there was felt to be an important role for champions as a point of contact for young people, so not just championing participation to other professionals:

"[I] we had posters up [in a service, with information on] where you can phone in, you can talk to this champion if you think you had concerns about anything going on with your clinician, and it not necessarily being a clinician who was that champion, just somebody who could go back and say 'look [this child is] worried about this'."
Health professional, CCHP staff and YP workshop 1.4

While the need for participation to be championed was seen as very important in CCHP, there was also a tension between the idea of 'participation champions' and participation being something that was 'everyone's business':

> *"[Participation] was becoming [seen as] the participation champion's responsibility… and obviously it should be embedded in the whole team effort".*
> Health professional, CCHP staff workshop 1.2

In the CCHP participation champions were both those with expertise and formal responsibility for participation (Barnardo's) and managers and staff in CCHP services. But it was felt that the role of service champion should not be limited to clinical practitioners:

> *"I actually said I would be the [area participation] champion…and was told that I wasn't allowed because [CAMHS] wanted it to be a clinician. I said I've got a daughter with a learning disability and I am really into making sure that her rights are upheld… if there was a child who was unhappy with [the service]…they could come to me and I could be that mediator but I was told 'no, it shouldn't be you as a manager, it has to be a clinician'."* Health professional, CCHP staff workshop 1.2

> *"Some of our most effective participation champions have been admin staff. I'm thinking of somebody at [head office] who keeps the 'You Said We Did' board going and was really engaged [with participation], and actually they are often the first people [children speak to] on the phone and when they come in".*
> Health professional, CCHP staff and YP emerging findings meeting

There can be an assumption in the literature on participation that power is something which adults have and can choose to share with young people. But in order to share power with young people professionals need to feel that they have a say in service and organisational decisions. The first quotation above certainly suggests that, as came up in the critical inquiry workshop, *"the structures and hierarchy within the NHS and other public bodies in particular don't [always] support participation or power-sharing"* (Brady, 2013, p.4).

In the Y-SBNT study my fellow public involvement lead and I took on the role of participation champions in the sense that we were specific members of staff *"dedicated to the development of participation"* (Wright *et al.*, p.24). Although we were not a permanent part of the system given that the Y-SBNT study was a time-limited project, we were recruited specifically to develop participation in the study. As with the CCHP this championing included cascading participation and driving implementation of plans, as well as being a point of contact for young people involved in the study:

> *"Young advisors will be supported by Louca-Mai and [other PI lead] to work alongside the research team in order to ensure that the [Y-SBNT] intervention is acceptable and relevant to our target groups, and reflects the views of service users and their families".* Y-SBNT PPI plan V.2, p.3

As with the CCHP there was a tension between the idea of 'participation champions' and wanting to make participation more of a collective endeavour:

> *"All project team are signed up to PPI in theory, but…I'm spending a lot of time responding to emails about things people are doing with 'what about involving YP [in that area of work]?' "* Research journal, 16/10/13

The research team championed participation at the start of the study by making public involvement a key aspect of the research design, recognising the need for specific expertise and ensuring that there was a reasonably generous allocation for young people's involvement in the overall budget.

10.1.4 Young champions

An important way of catalysing change is by involving young people as young champions (Kirby *et al.* 2003), and the young people involved in both case studies were clear that they wanted to use their personal experiences to benefit their peers. The two young people with the longest involvement as Y-SBNT young advisors also said that their main motivation for getting, and staying, involved in the study was to use their experience to benefit others:

> *"I wanted to get involved with this project because I've always wanted to do something like this to show others…that no matter what circumstances they're in they've always got a voice."* Young advisor A. Telephone interview

> *"I'm involved in the [YSBNT] project so I can pass on my experience…I want to make things better…I actually don't care as much what I get out of it….I just don't want to see any other young person suffering the way I had to, or end up dead or in prison. If I can help develop something that prevents that [the Y-SBNT intervention] then I will."* Young advisor B. Telephone interview

One young person involved in the development of the CCHP participation strategy also talked about how her personal experience had motivated her to champion young people's participation, and the benefits she had got from doing so:

> *"As a young person that has been involved with CCHP for nearly five years (and CAMHS for seven years), I jumped at the chance to become involved in developing the new 'Participation Strategy'…. the next step is to work together to make this strategy come alive…How do we communicate to YP what they can expect from good health care and what 'good' looks like in practice?… another young person and I worked with Barnardo's to produce a film of our participation journey [CCHP 2014b]. The past few years of our lives have been quite a difficult journey. We both agree that a big part of the progress we have made can be attributed to the participation we have been involved in. We made the film to convey the impact and difference good participation makes to individuals on a more personal level."*
> Blog post by young person involved in CCHP group (Hathway, 2014)

The role that young people played in participation practice will be explored further in the next chapter, but the quotations above highlight that for the young people involved in the case studies motivation to become a champion for participation was often about using their personal experience to benefit others, as well as personal benefits they might gain from being involved. Embedding a culture of participation involves consideration of the motivations of and benefits for young champions, and considering how they can most effectively be involved in catalysing change.

10.2 Planning participation

10.2.1 Structures and processes

Clinical trials have structures and protocols to follow, along with having clear lines of responsibility, budgets and a detailed timetable. The way in which health research studies are commissioned, ethically approved and monitored in the UK means that proposals have to demonstrate their understanding of the existing evidence. They also need to set out clearly how they intend to undertake all elements of the study – including public involvement – and regularly report back to both steering committees and funders. As we did not have any young people involved in the study until funding had been secured and planning was already underway our initial plans for participation were based on an established model for young people's participation in health research. However when the YPAG model proved not to be the right one for the young people we wished to involve it was relatively straightforward to develop a new approach and re-allocate resources within the structures and processes of health research. Any changes required approval from the TMG and TSC, and the funders had only to be kept informed as part of quarterly updates from the principal investigator. Although the day-to-day structures relating to the management of young people's participation in the Y-SBNT study were relatively straightforward and located within the study itself, it was necessary to consider the wider structures within which this and other health research operates:

> *"[This is not]…just about embedding in a particular project it needs to be embedded in the wider systems which are supporting that project so it needs to be embedded as a routine thing that clinical services are doing as part of everyday [practice], it needs to be embedded into the way that the local commissioning structure needs to work, it needs to be embedded in the way research funding structures work…So perhaps embedding is a whole system type of thing, we perhaps can't always expect it to function clearly and in a particular project if it's not going to be able to function when you have to have contact with those other bits of the system."*
> Research team member A, Y-SBNT TMG focus group

As with the CCHP this suggests that the structures and systems in the NHS, social care and health research can both enable or present barriers to the embedding of young people's participation in studies such as Y-SBNT.

The structure of CCHP was in itself fairly complex, as well as being part of the wider NHS. It was a large organisation delivering a range of services across a large geographical area. But this made structure and process all the more important:

> *"…some services or individuals [in the CCHP] are maybe doing participation really well and other services maybe not so well, and…it needed to be a universal thing so there were no gaps…the systems and structures…needed to be in place to support that."* Health professional, CCHP staff workshop 1.1

> *"We really do involve children and young people a lot in the [CCHP] services, but it is about tying it up, it is about actually putting structures and systems into place…we know that we do [participation] but we need to demonstrate that we do it and we need to find a way of making sure that everybody does it in a similar way".*
> Health professional, CCHP staff workshop 1.1

Linked to the importance of a shared vision and management support was the need to build in processes and infrastructure which supported participation:

> *"If you've got a real sort of infrastructure [for participation] in place, like a whole systems approach, and everybody is on board…then everything else…should follow suit…it's about people making sure that that system or that process or whatever you want to call it is really robust and everybody's clear and aware of it and I think then everything else can sort of feed into that".*
> Health professional, CCHP staff workshop 1.2

Impending changes to the CCHP (see 6.1) meant that long-term planning was difficult. However it also provided opportunities to review how well current organisational structures supported or created barriers to participation:

> *"We would need to be looking…almost evaluating this current [organisational] structure…the strategy, the [framework] and this [mapping exercise] need to triangulate together don't they?…maybe that would then be a way of identifying what's the strengths and weaknesses are in this [current organisational] structure…So, it would be part of the action of how we're going to achieve what we need to achieve in the next two years."*
> Participation worker, CCHP staff workshop 1.1

The participation manager led an exercise in the second workshop which tried to map all participation activity with CCHP services; the structures to support young people's participation in service development and review processes; and how young people's participation could be supported by organisational processes including induction, training, staff recruitment and appraisals (see Appendix 6):

> *"I think to be positive, there is a lot going on. It is how it connects and relates to each other that is my biggest concern, so it is not to say that nothing exists, but it often exists in isolation of something else and it is not linked. Young People Friendly is probably the best example of how something links to something else that links to something else… it has a very robust structure in place, although the down side to it is it is an enormous amount of work, so very few services have achieved it".*
> Participation worker, CCHP staff workshop 1.1

Participation was certainly happening in CCHP. The challenge was finding out what was happening and making sure it was underpinned by common standards such as Young People Friendly, hence the identified need for the participation strategy and framework.

10.2.2 Developing plans and standards

Building a culture of participation requires the development and communication of *"public promises to give a specified quality or level of service"* linked *to "progressive targets"* to improve performance, which should *"build on what is already in use"* (Cutler, 2003, p.5):

> *"Many participation guides emphasise the importance of developing a charter or standards for participation on which the organisation's practice will be based."(*Wright *et al.* 2006, p.19).

In both case studies our approach to young people's participation was built on existing models, tools and resources. Initial plans for young people's participation in the Y-SBNT study (Copello *et al.*, 2012) drew on the literature on young people's involvement in health and social care research and an established model of participation (the YPAG). This informed an initial 'PPI plan' which I drafted in consultation with the other public involvement lead. The plan included details of how and when young people would be involved in the study, key milestones and how this participation would be evaluated. The plans underpinned the day-to-day work of involving young people in the study, as well a means of documenting how and why our plans for plans for embedding young people's participation changed as the study progressed and the PPI plans evolved. The plans were also an attempt to get the research team to engage with participation by setting out responsibilities, issues to consider and suggested actions and milestones, which in turn informed actions allocated to people in minutes of TMG meetings. How successful they were at doing this is discussed further below.

From the outset there were limits to young people's possible influence on the Y-SBNT study, not least because the study was based on an existing adult intervention:

"We have [already] got a basic design [for SBNT] and the PPI will influence the content of the [adapted Y-SBNT] intervention and the design". TMG minutes, 06.13

This meant that there were things that could not be changed because they were core elements of the original SBNT intervention. The lack of early resource for participation prior to the study, or a willingness from the study team to find a way to involve young people prior to the trial starting meant that participation methods needed to be specified before it was possible to involve young people. These factors certainly made it harder to embed participation in the study but the fact that the plans evolved to reflect the learning that emerged during the study, once we did have young people's input, was really helpful.

With the CCHP the process of developing the participation strategy was a collaborative process and the strategy was where we ended up rather than where we began:

> *"Doing this [developing participation strategy] as a group I think it produces something better and the process is so much better, but it is so much longer. You have some final decision-makers but you really want to feel that people are having their say and that you're listening to them and taking account of what their feedback is. We are certainly doing our best to do that."*
> Participation worker, CCHP staff and YP emerging findings meeting

Vignette 2 below outlines the process of developing this participation strategy.

Vignette 2: Development of the CCHP participation strategy

During my initial discussions with CCHP managers they identified a need to develop a coherent participation strategy in order to create more consistency across services and provide some guiding principles:

> *"[This] strategy needs to actually set the culture, the ethos, of the organisation".*
> Health professional, CCHP staff workshop 1.2

When this approach had been agreed by the staff and young people involved in the workshops we began exploring people's views what the strategy should look like. Participants agreed that it should be set the culture and ethos for participation, and focus on values and principles that would be linked to key indicators set out in a related participation framework, along with and a leaflet for children and young people. The plan was that the draft strategy would be developed during the first cycle of workshops and then finalised by Barnardo's after piloting in the second cycle. Once it was signed off and disseminated, services and areas of CCHP would then be expected to develop a participation plan using the framework and strategy and report back on this. Broadly this is what happened, other than the young people deciding to make a film and poster instead of a leaflet, and the roll out and dissemination being slowed down by the earlier than expected recommissioning of CCHP (see 6.1).

The final strategy states that the CCHP's ambition was:
"…to establish participation as an everyday process - understood, valued and acted upon by professionals and children, young people and their parents/carers. The CCHP self-assessment framework of participation standards means that services and functions can apply this strategy to the work they do". CCHP Participation Strategy, p.2 (Appendix 7)

The intention was that the strategy and associated framework (Appendix 7) would be a starting point both for the development of participation in CCHP services and, hopefully, a vision and statement of intent for commissioners and potential new contract holders. It was hoped that the associated film (CCHP, 2015a) and other materials developed by young people would similarly raise awareness of participation amongst current and potential users of CCHP services. How this played out in practice is discussed further below and in the Chapter 11.

[End of vignette]

It was important that the CCHP strategy be accessible and engaging, particularly in a busy professional environment:

> *"[W]e need to make it clear to professionals and anyone reading [the participation strategy] really: 'why is this important to me and why should I read this document? On top of all the other documents that I've got to read'...it needs to stand out and it needs to say: this is different and this is important".* Health professional, CCHP staff and YP workshop 1.3

There needed to be a balance between creating a shared vision and individual services and practitioners having a sense of ownership for something they felt was manageable and relevant to them:

> "*If we have a strategy that fully represents every single service and every single service user, that would be a 200 page document. ..[but if] we create something that is relatively high level, that can be applied to everybody, so it doesn't exclude anybody, but then it is down to [services] to say 'how does this high level guidance, standards and values relate to my service, my families and the age range and the needs that those families have'. It needs to be able to do that but it cannot include the detail because it is going to be too unwieldy...There will be holes in [the strategy] because of course they didn't input into it and [I'm]...thinking about how you involve the wider staff and children, young people and families in how we develop service plans and strategies, so the work doesn't stop [when the strategy is completed]".* Participation worker, CCHP staff workshop 1.1

The quotation above highlights the importance of such a strategy being inclusive but not all-encompassing, a 'live' document which can be adapted to be relevant to particular services and service user groups, as well as incorporated into other planning and service development processes. It was therefore important to work collaboratively with services, children, young people and families in implementing and reviewing the strategy, reflecting the fact that the strategy and framework emerged from a collaborative process:

> *"We all need thinking time in order to make something feel like it's got a good foundation and that it's got enough diversity of different people's opinions in it, because we wouldn't have been able to create [the strategy] without the different types of people who are in this room [and] some people who are not in this room...there's no way Barnardo's or young people or [CCHP] staff could have done this on their own. It's quite a powerful demonstration to me of how much better things are when you [create] them from different type of perspectives."* Participation worker, CCHP staff workshop 1.1

From this collaborative process emerged the idea of a concise, over-arching strategy accompanied by a framework which would support services to set outcomes and outline the ways in which young people would have opportunities to participate in their service (Appendix 7). The CCHP participation strategy and framework were also important in identifying gaps and areas for development:

> *"My hope is that the strategy will help to create some order and some sense of systematic consistency about when [a participation project or initiative] is introduced."* Participation worker, CCHP staff workshop 1.2

In the Y-SBNT study, as discussed above, the study proposal created the initial framework for outlining the process by which young people would have the opportunity to participate in the study:

> *"[At the start of the study] I was thinking that the great utility would be for young people to be involved in the development of the [Y-SBNT] intervention…Because I was very much involved in writing the proposal and at that stage I was thinking, I could see a very clear function [for YP's participation] there".*
> Research team member E, Y-SBNT TMG focus group

Plans for participation built on this as the study progressed and our model for involving young people evolved. In reflecting on whether Y-SBNT PPI plans and the CCHP strategy were effective participation standards I found it helpful to draw on the work of Cutler (2003), who suggested that effective standards for children and young people's participation should "*be easy to understand, public and testable"*, take into account the culture and type of organisation, *"build on what is already in use*", trigger organisational action if standards are not met, *"link to real outcomes and be supported by adequate resources*" (Cutler, 2003, p.5). These criteria are more directly applicable to the CCHP, as a participation-focused organisation, and the final strategy certainly sought to meet all these criteria. How successful the organisation ultimately was in doing this would be an interesting subject for a follow-on study, as the implementation of the strategy and framework was only just getting underway when my work with the CCHP ended.

In the Y-SBNT study the standards suggested by Cutler (2003) were certainly considered by myself and the other public involvement lead but collective consideration of these issues tended to be limited to TMG meetings. Failure to meet standards triggering organisational action was not directly relevant to the PPI plans, as these were 'live' documents which evolved to reflect our attempts to find ways to involve young people in ways that worked best for them, rather than being standards against which we could fail. Although we did have to update the funders on participation activity as part of the study's quarterly reporting this just involved outlining how what we were doing related to what had been set out in the proposal and study protocol, rather than demonstrating that we had met any specific standards. The practical application of these issues is considered further in the chapter which follows in relation to practice and review. But I would question how helpful it is to talk about failure to meet set standards rather than a process of reflective practice and collaborative learning, in which people are encouraged to reflect on challenges as well as successes. So rather than talking about 'failure' triggering organisational action it is more helpful to say participation standards and plans need to be 'live' documents which are reviewed and revised as circumstances change and in response to feedback from professionals and young people. But whatever form it takes, in order to embed a culture of participation this study found that any charter, standards, plan or

strategy needs to be something on which practice can be based and against which progress will be measured:

> *"[I]f you see the [participation] strategy in terms of the culture, structure, practice and review, all these things will need attention won't they? And that needs to be the structure of the strategy as well".* Participation worker, CCHP staff workshop 1.2

This references Wright *et al.*'s (2006) whole systems approach, which formed the core structure of the CCHP participation strategy as well as informing the theoretical framework for this study.

10.2.3 A charter for young people

Wright *et al.* (2006) suggest that a participation charter should be something that should be *"agreed and signed by each child, young person and adult joining the organisation"* and that *"children and young people should take part in regular reviews of the charter"* (p.19). Cutler (2002) proposes that *"young people will need to be involved throughout the entire process of [participation] standard setting*"(p.22). But is this something that young people necessarily want? Also what validity does this approach have for young people yet to participate? Both Wright *et al.* (2006) and Cutler (2002) appear to assume a model of participation in which children and young people have ongoing involvement with an organisation, and also that they will be interested in being involved in the management of strategic participation. Neither of these things was the case in this study: it's arguable whether many young people accessing health services such as the CCHP see themselves as 'joining' an organisation or community of practice, or are necessarily interested in developing, signing or reviewing participation standards. The idea of a 'participation charter' also doesn't necessarily work well for time-limited projects like a research study particularly when, as was the case with Y-SBNT, there was not a core group of young people involved throughout the study. The nature of research commissioning meant that every member of the research team was involved in agreeing standards for participation and the senior investigator and others shared responsibility for their implementation and monitoring. But, as with the CCHP, we found that this was less important for the young people we were seeking to involve. They were able to see and contribute to participation plans but their interest, and the requirements of the study, meant that their focus was much more on the content and implementation of the Y-SBNT intervention than reflecting on the process of participation.

In the CCHP young people were involved in the first series of workshops which informed the development of the participation strategy:

> *"We [young people involved in CCHP workshops] wanted to be involved in developing the strategy to help embed participation on every level across the partnership. Drawing up this strategy gives participation the same importance as any other policy*

and provides a standard and formal tool for professionals to measure their performance against." Blog post by young person (Hathway, 2014)

The plan had originally been to develop a participation strategy which was relevant to practitioners, young people and their families as illustrated by the following exchange between health professionals at the second CCHP workshop:

"No, I don't want a young person's version either.
"I don't, I have a real issue with having two versions of things…It's just a way of separating, isn't it really?
"The thing is though you've got to remember it's not just children and young people, because adults look at it and think I don't understand that. So, if you write it in a way that children and young people are going to understand it, the adults will as well."
Health professionals, CCHP staff workshop 1.2

However young people had a different view, especially when it became clear that what was needed for the development of organisational practice would not work for young people and vice versa:

> *"We [group of young people involved in the workshop] had quite a hard time trying to read through [the draft strategy]…because we felt it was too wordy and that the meaning was sort of lost because it was taking so much energy to read all the words….we all thought that maybe the idea of having a poster of the values…re-writing them in a more simple way [would be better], we couldn't…understand how you can only have one version of [the strategy] really, how one version could meet all the needs of staff, parents and young people and we thought a poster would be good and we would have a cool time designing it".*
> Young person, CCHP staff and YP workshop 1.3

> *"[I]t's really difficult to enthuse young people about strategies and policies…that's been a bit of a challenge for us, the fact that the whole process is trying to actually make the strategy come alive, to make it interesting and relevant [to young people]. It only comes alive when they can relate it to their own experiences and then they…understand what it's about more. Especially from the children's rights angle, a lot of young people get passionate about 'oh we need to make it better for other young people, they don't want to go through the same thing that I went through and we need to change that'. If you frame it in that sort of way then [young] people seem to have an interest in what is actually in the words of a strategy".*
> Participation worker, CCHP staff and YP emerging findings meeting

The above quotations make important points about participation needing to be meaningful and relevant to young people, as well as illustrating how the reality of participation can differ from the rhetoric. Although the principle of involving young people in the development of the strategy was a sound one, we found that this did not always work in practice. The group eventually came to the decision that they wanted separate but linked documents for CCHP staff and young people using their services:

> *"Agreement from staff, YP and core group that the strategy should be for CCHP staff, as they will be the ones implementing it, but that it should be accompanied by a poster (designed with YP) accessible to YP and parents, which should be displayed in all CCHP services and offices, as well as a leaflet about children's rights and the CCHP 'offer' given to all new patients and available at all CCHP services".*
> Research journal 15/01/2014

Once this had been decided the participation manager led the further development of the participation strategy and framework, and young people involved in the project worked with Barnardo's to develop a film and poster letting young people know about their right to have a say in CCHP services. The young people's idea of a film and poster also links to the idea of awareness as a process of capacity-building for participation discussed in the previous chapter, as well as ideas of ownership and collaboration. My active involvement with the young people involved in the strategy workshops ended before they began this work. At the end of the first phase I moved on to the workshops with the group of professionals piloting the draft strategy and framework, and Barnardo's worked with young people to develop the film and poster:

> *"[Participation manager and I had] talked about the possibly of my having a meeting with the YP to review their involvement in the first cycle and discuss how they'd like to be involved in the next. But when we spoke on Tuesday she said that this could be tricky as there were a lot of other things the YP needed to do that week. It also sounded like a lot of these conversations had already happened, and that the YP were quite clear about what they wanted to do next (focus on developing YPs versions of strategy materials) and that they and [Barnardo's workers] were busily taking this forward without needing any input or steer from me… I realised that this was…about my allowing this to be a real collaborative process…to be embedded and have a life beyond this project the strategy needs to be owned and taken forward by the people involved".* Research journal 17/05/14

This was about ownership and responsibility for me as well as the young people and professionals involved in the study. However much I had invested in the development of the strategy and was committed to young people's involvement in it, my work with the CCHP for this study was focused on the initial process of developing and piloting the strategy rather than its ongoing implementation. The fact that it continued so successfully without my input is testament to the collaborative process and the fact that we had managed to create something for which those involved felt a shared ownership. As one of the young people involved said at the end of the process:

> *"I really felt as though we were an equal group and that there was no disparity between YP and staff….I left feeling really hopeful that this collaboration was definitely the way forward and the thing that was going to make this [participation] strategy authentic and meaningful."* Blog post by young person (Hathway, 2014)

However while the process of developing the strategy was certainly collaborative, something did get lost when the staff strategy and YP's dissemination plans became separate pieces of work. Some of the young people involved wrote a cover letter in April 2014 which was intended as an introduction to the strategy. After I queried the absence of this from a draft of the strategy it was included as an appendix in the research summary produced in August 2015 (Appendix 8), but somehow this letter was not included in either the final strategy or framework (Appendix 7). There was also no explicit link between the film and participation strategy when it was first put on the CCHP website. This meant that

staff and other professionals who saw the strategy may not have been aware of the young people's letter or film, and that young people and families who saw the film may not have been aware of, or had easy access to, the participation strategy and framework. As I was not involved in the development of the final documents I am not sure how or why this happened, but it does seem like a missed opportunity to have young people's voices at the heart of the strategy and to explicitly link the professional and young people's outputs. It is possible that the upheaval caused by the recommissioning, which included moving the CCHP website from the health trust to the interim contract holder, meant that this got lost somewhere along the way. It also illustrates what can happen when attempting to implement initiatives such as this in the face of the realities or organisational practices and processes.

The nature of young people's involvement and the model of participation which emerged during the Y-SBNT study meant that it was not possible to involve many of the young advisors in the development of the participation plans discussed above. However we regularly sought their feedback on how we were involving young people in the study and this informed revisions of the PPI plan, which we then updated the young people on via the newsletters (e.g. Appendix 10). But as with young people working on the CCHP project, many of the young people involved in the Y-SBNT study were not keen on reading long formal documents:

> *"Personally, if I was to see something on the internet or on a piece of paper, I probably wouldn't be that interested, I like to see people and be able to find out about things face to face if I can".* Y-SBNT young advisor A, phone interview.

This was not the case for all young people involved in the study and indeed a couple involved earlier on asked for a copy of the full SBNT manual on which the Y-SBNT intervention was based. But both those young people then left the study and the ones who were involved later on were much more interested in the practical application of the study. This again highlights the need for participation to be directly relevant to young people's lives and responsive to their priorities and interests, not just benefiting services or research. The main way in which young people were involved in Y-SBNT participation plans was in their contributions to the development of a new model for young people's involvement in future studies of this nature:

> *"Ideally you should start setting up a group of young advisors a year or so before the study begins. Young people could then be involved in proposal development and possibly developing films and other materials about their experience which could be used in training and recruitment. We would also like to be involved in a few different projects, not just one".* YP's feedback from young advisors' meeting, April 2015

The ways in which health research is commissioned, funded and regulated can make it difficult to develop participation in a truly collaborative fashion. There is also the question,

as with the CCHP, about whether it is sometimes preferable and more accessible to have parallel documents or other information sources for adults and children and young people, for example the participation strategy and framework alongside the young people's film and poster in CCHP, and the study proposal and PPI plans alongside more accessible information for young people in the form of information sheets and newsletters in the Y-SBNT study.

For CCHP staff having a clear, organisation-wide vision and standards for participation for all staff across the organisation was central to embedding participation, hence the strategy and framework. But in health services like CCHP children and young people come and go, and may talk about seeing a physiotherapist or going to CAMHS rather than identifying themselves as a user of CCHP services. Perhaps this model may work for the young people who work with the Barnardo's HYPE service in strategic or service-development related participation activity, but we wanted something that would be relevant to every child and young person coming into CCHP services. Therefore the materials developed by young people focussed on informing children and young people about their right to have a say in the services they used, rather than being something to which they needed to 'sign up'.

10.3 Resourcing participation

In both case studies young people's participation was allocated a ring-fenced amount of the overall budget. But having to detail and anticipate costs in advance did present some challenges in the Y-SBNT study:

> *"This other model [of YP's involvement developed during the study is] ...a break from the usual scenario and maybe...it shouldn't be a structured thing. Putting a budget on PPI is hard because it should be reactive and it should develop over time to some degree but that said I still think there's the potential for it to be more individual based."* Research team member E, Y-SBNT TMG focus group

While the Y-SBNT public involvement budget was fixed the spending of it varied considerably from our original plan, in which most of the non-staff money was going to be spent on a series of large group meetings. Instead we ended up having more small or one-to-one meetings with fewer young people. We also completely changed the way in which young people were paid. In many YPAGs young people are given a gift voucher for their time and this was the model we initially adopted: all young people involved received reimbursement of travel expenses and, initially, a £20 voucher for each meeting attended. But when we realised that we were going to have fewer young people involved in the study, and that loss of income was a barrier to involvement for some, we decided to adopt a different approach and pay young people an hourly rate, as well as travel and subsistence expenses as before (see 7.5.1). This was managed within the overall budget so had no

resource implications beyond agreement by the TMG and TSC and informing the study funder. However having flexibility within a fixed overall budget was important both in relation to payment and because the budget was spent differently as we sought to work in ways that worked best for the young people involved. However having a reasonably generous public involvement budget did put pressure on us to deliver:

> *"[I'm] just describing an objective view but someone looking in our project would see that the PPI budget is one of the biggest slices of budget in the project. So they'd be asking what's been the benefit of that?...What is the extra that it brings that wouldn't have been there?"* Research team member B, Y-SBNT TMG focus group

Although young people's participation in the study was judged a success by the TSC and independent reviewers of the draft study report, we needed to justify to the funders how that money had been spent. Although it is important to evidence impact (discussed further in 11.5), this was not easy when we were struggling to find and keep young people involved in the study. It also raises questions about the need to prove that participation is offering 'value for money', particularly when seeking to involve young people who may need additional support or more flexibility. But there is conversely, an argument that not doing participation meant that services (or research) are not as effective:

> *"[I]f you look at it from a...budget-holding point of view, you're actually wasting money by not listening [to children]. Because it's not going to be an effective intervention, [children are] not going to benefit from it...So, actually you need to invest in [participation]. It's going to save us money [in the longer term], isn't it*? Health professional, CCHP staff and YP workshop 1.4

The CCHP was unusual in that it was a jointly commissioned health organisation in which Barnardo's was funded to lead participation. But even so finding the money for participation activity in services could still be difficult, particularly at a time when resources were stretched in terms of NHS budgets and staff:

> *"In the NHS quite a lot now they don't have money apart from to pay the staff and to heat the buildings etc, etc, and some admin costs. There aren't that many things that [services] can pay for in addition to that."*
> Participation worker, CCHP staff and YP emerging findings meeting

This limit on resources could be something as simple as the fact that the physiotherapists piloting the implementation of the strategy were unable to print a leaflet in colour even if this made it more young person-friendly. There was also discussion in the development of the participation strategy and framework about needing to set a baseline for participation which was both ambitious but also realistic and achievable within existing resources *"It might not be enough, but it's all you can do [with the available resources] isn't it?"* (Health professional, CCHP staff workshop 1.2).

It was considered important to be realistic as well as ambitious for the long-term sustainability of participation in the CCHP, but alongside this it was acknowledged that

some additional initial resource would be needed for the development and implementation of participation practice, so a small budget was set aside by Barnardo's to support services with additional expenses during the roll-out of the participation strategy and framework:

> *"We have…decided to attach a budget to the participation actions that people have [when they're implementing the strategy and framework], so that it values what people are doing which is essentially, to start with, extra to what they are [normally] doing…It won't be embedded to start with."*
> Participation worker, CCHP staff and YP emerging findings meeting

Barnardo's also provided practical support during the piloting of the strategy and framework in the physiotherapy services:

> *"It is quite a skilled process that you have to go through in order for [young] people [and families] to feel comfortable enough to say [what they think about services] and it's not straightforward…I think let's get this working [in the physiotherapy services] first with the support [from Barnardo's] to then focus on the feedback [from young people and families] and how that feedback is used, and then think about what internal resource is needed to support that as well as Barnardo's…so resource-heavy to start with and, as people's confidence and people's sense that this is a useful thing to do [increases], this will then hopefully become more integrated into what you're doing as a group [of services] anyway".* Participation worker, CCHP staff workshop 2.2

Participation expertise is also a resource. The role of Barnardo's was key to supporting the embedding of participation in the CCHP, but they were only a small team (at the time I worked with them there were eight full-time equivalent Barnardo's staff compared to over 800 NHS Trust staff), so they needed to consider how best to use their resources. The roll-out of the participation strategy was therefore a gradual process which had only begun when I finished my work with the partnership, and was slowed down further by re-commissioning.

There was a further resource issue in the CCHP in the need to consider administrative support for participation, something which workshop participants felt was often overlooked:

> *"[Participation]…it's not [currently] seen as part of any admin person's role. So when you come to try to do some sort of project then everybody goes 'well, I haven't got time to do it'."* Health professional, CCHP staff workshop 1.2

Similarly in the Y-SBNT study the other public involvement lead and I spent more of our time than anticipated on administration, recruitment and following up young people compared to face-to-face participation activity. This was partly because it was a lot more difficult than anticipated to build an established group of young advisors, but also highlights a wider issue about the need consider resourcing the administration of participation.

10.4 Conclusions

This chapter considered how structures and systems in the two case studies supported or challenged the embedding of participation. The study found that a shared commitment to participation needs to be balanced with leadership, particularly in management, for participation practitioners, maintaining participation on the agenda and addressing resistance to change. Alongside this there is a tension between the need for participation champions and expertise and the idea of participation as a collective endeavour, as well as recognising that young people can and should be participation champions too. Planning participation requires a framework for setting outcomes and outlining the process by which young people would have opportunities to participate, but this needs to be considered within the wider context of NHS and health research structures and systems, which both enable and create challenges to the embedding of young people's participation. The changing nature of how NHS services are commissioned, delivered and funded creates particular challenges to embedding participation in health services. Similarly it can be hard to embed participation in the study from the outset when seeking to involve young people who are less likely to be members of established young people's advisory groups.

Although setting standards for participation was found to be important, this study found that it is more helpful to construct this as a process of reflective practice and collaborative learning than failure if standards are not met. Standards also need to be 'live' and flexible enough to adapt to the changing needs of services and young people. The literature suggests a model of participation in which young people have ongoing involvement with an organisation, and also that they will be interested in being involved in the management of strategic participation. However young people using health services may not have ongoing involvement with an NHS service and young people may also move in and out of involvement in a health research study, as was the case with Y-SBNT. The question is whether this matters or whether there are other ways for participation to be meaningful for children and young people, something which I will explore further in the next chapter.

The emerging learning from this chapter suggests that embedding a culture of participation involves an ethos and commitment to learning with and from young people in joint and collaborative processes. So in the next chapter I will explore how this might happen: how people in the two case studies worked within and beyond the culture, structure and systems outlined in the last three chapters to embed participation in practice.

11. Rhetoric to reality: embedding participation in practice

In the previous three chapters I considered how participation was understood in the two case studies, how these understandings informed cultures of participation, and how structures and systems can enable or constrain the embedding of participation. In this final chapter I explore how people in the two case studies worked within and beyond the culture, structure and systems outlined in the last three chapters, as it was in practice that the embedding of participation was thought to happen:

> *"[E]mbedding means [that] it becomes everyday and routine. It's not a bolt on extra task…it's just normal to think about [participation] as part of the project."*
> Research team member A, Y-SBNT TMG focus group

> *"I think there's something about taking the theory and the concept [of participation] and going 'actually there's practical thing we can do and what that actually looks like on a day-to-day basis'."* Health professional, CCHP staff workshop 2.2

This chapter considers what 'good practice' looked like for practitioners and young people, how the practice of and capacity for participation was developed, how both the process and the impact of participation were evidenced and the implications of adult-driven structures, systems and processes for participative practice.

11.1 Professional practice in health services

In the Y-SBNT study professional practice was intertwined with the research process, particularly in relation to my role and that of the other public involvement lead, but also for other members of the research team when they engaged with the young advisors. Vignettes 3 and 4 below explore this in more detail but the section which follows focuses on the practice of healthcare professionals. In the CCHP participants thought that participation was already embedded in processes such as recruitment and training, but that more work was needed to develop participation in other areas:

> *"[W]e already involve young people in interviewing and training, which is great, but we really want to develop that, and I think, well we just want to develop everything, keep pushing [participation practice forward]."*
> Health professional, CCHP staff workshop 1.1

Much of the discussion on what young people-friendly participation might look like in practice focused on individual-level participation in services, as this was felt to be the area most in need of development. When piloting the strategy with the physiotherapy services there was a realisation that individual participation was often still fairly parent-focused:

> *" [W]e were just thinking about whether we would be want to ask the child questions [about their concerns and expectations of treatment as well as parents], so [in the] initial assessment review….to include on our paperwork, so it's there in black and white, so we don't forget to ask [the children for the views]."*
> Health professional, CCHP staff workshop 2.1

The idea that even a well-intentioned and participation-aware practitioner might *"forget to ask"* a young person for their views during an assessment illustrates how far from embedded participation can be in everyday healthcare practice. Similarly the often inflexible and geographically-bound way in which services are delivered, even within an organisation, can create challenges to planning services according to what works best for young people:

> *"For example there [might be an issue for a child] around [when they have] hydrotherapy... we can actually give [children] choices by just being a bit more open, we are a partnership-wide service and we ought to think of ourselves as such".* Health professional, CCHP staff workshop 2.1

This suggests that embedding individual participation effectively in health services requires changes to processes (e.g. paperwork), working across services and area boundaries and for practitioners to reflect on how they can best integrate participation into their own professional practice. This also needs to be done in ways that work for individual young people, acknowledging the power dynamics at play:

> *"[W]e talked about ensuring that children's opinions are asked..[but] sometimes an initial assessment is not the most appropriate time to say to a seven year old 'so, what do you want to talk about?'. It might take a couple of sessions with that child for them to feel comfortable enough to say that. And give the child some choices...some degree of power over what's happening to them, as opposed to just launching in and doing."* Health professional, CCHP staff workshop 2.1

Although these concepts are frequently cited in the policy and guidance discussed in Chapter 3, cultural tensions between medical models of treatment and participation created challenges to implementing the rhetoric of participation and rights in the CCHP when faced with the realities of clinical practice. It is overly simplistic to say that healthcare practitioners should work at a young person's pace when, as with most public sector services, they are often too pressurized to do so. But the learning from the CCHP case study suggests that embedding participation in healthcare interactions requires the practitioner to have a good understanding of participation as well as their professional responsibilities.

Developing confidence and competence in participation

CCHP participants identified a need to create opportunities for shared learning in relation to both individual and strategic participation:

> *"One of the things they [health professionals] talked about was shadowing each other a bit more...one of the consultants said 'well, I might be really rubbish [at talking to children]. Nobody's checking whether I'm any good or not'. I think when you work on your own, there is something about the fact that your skills are very hidden and you might have some amazing skills or you might have some things that you really need to work on."* Participation professional, CCHP staff workshop 1.2

> *"We've done this work [piloting participation strategy and framework] and should we then share it with our colleagues and professionals?...they might be interested to use the things that we've developed, they might have other ideas and then they might hopefully want to do [participation]...[because there's] no point just telling people we've got to do it. It just doesn't work, it has been tried for a long time."*
> Health professional, CCHP staff workshop 2.2

There was awareness that even very experienced health professionals may need support in addition to the strategy and framework for participation to become embedded in their practice:

> *"[P]eople...get a bit anxious about [participation]...or think actually it's going to be a lot of extra work, but if they have got a box of tools... like [this] feedback form for my therapy group....sometimes people just need those prompts, those tools to be able to pull from rather than have to go away and think up their own, so how we do more of that?"* Health Professional, CCHP staff and YP emerging findings meeting

The idea behind the strategy, framework and associated support from Barnardo's was that this would enable staff across the organisation to develop the confidence and competence to embed participation into their professional practice:

> *"[How do we] move from where we have possibly been in the past... [from] novice to expert...currently lots of people are very conscious about what they are doing and the detail and the hard work that it [participation] takes. But [we want to be] actually moving to that expert approach, where you are subconsciously competent at what you do and you don't even think you are doing it, like driving a car, [that] would be just a fantastic place to end up".* Participation professional, CCHP staff workshop 1.1

This idea of 'subconscious competence' suggests a point at which participation would be truly embedded in a health professional's practice, when it was something they felt comfortable and confident doing which was integrated into how they did their job every day. Making it a gradual process also has the advantage of allowing the tools and process to evolve and be adapted to different services and young people, as well as for learning to be shared. CCHP had done something similar with Young People Friendly (YPF) (4YP, 2014) where services received intensive support from Barnardo's to gain YPF accreditation, and praise and publicity once they had achieved this.

Embedding participation in everyday practice

In a large and complex organisation like the CCHP participation needed to be embedded through an ambitious but gradual process:

> *"I wonder whether it's quite good to do some detailed work with a group of staff as a pilot, to be able to then share that experience with others. It's just such a big task [to roll out that strategy across] the partnership...if we [just] present this as a strategy...I'm a bit scared about what we might get back, actually, from some people...I don't want it to be presented as this is an option for you to say well...I'm not doing that."* Participation professional, CCHP staff workshop 1.2

Embedding participation involves making this an expected part of everyday practice, but also keeping things manageable and realistic:

> *"I think the one lesson is not to take on too much. Something small that you can actually change rather than anything huge that actually you can't really do very effectively. I think [participation] is far more embedded within the culture of physiotherapy now that we've gone through this process [of piloting the strategy and framework]. I would say that has helped us embed it more within our culture of working."* CCHP staff and YP emerging findings meeting

The physiotherapy staff were able to embed participation in their working practices because of the support they received from Barnardo's as well as discussions during our meetings together for this study. But although Barnardo's were a key partner, they did not have the staffing to effectively support the roll-out of the strategy and framework across all CCHP services simultaneously.

11.2 Young people's views of good participation

Personal benefits

Echoing the existing literature the young people with whom I worked in both case studies were clear that there should be benefits in terms of learning skills and gaining experience: *"[Tell young people that] it's not just having a chat you are learning skills that are going to help you."* (Y-SBNT young advisor A, one to one meeting). They also talked about the importance of seeing how their participation has made a difference and feeling valued:

> *"The fact that you've included so much of the young people's material [in the draft Y-SBNT study report chapter] completely personifies the whole point of the project. It's the first time a group of professionals have taken things I've said and made use of it, and benefitted from it, in an academic project. I'm very much used to discussing my substance use history in a very negative light with no real benefit at the end but this project has helped me realise that a negative experience has made me wiser."*
> Y-SBNT young advisor B, one to one meeting

The above quotation highlights the personal benefits of participation for young people who have been able to bring difficult personal experiences into their participation work, something which also came up in the CCHP:

> *"I've learnt new skills [through being involved in participation], regained the confidence and purpose that my mental illness had unceremoniously stolen and gained voluntary experience that has helped in applying for jobs and university. This work has revealed my passions and convictions, allowing me to carve out some direction in my life".* Blog post by young person (Hathway, 2014)

> *"[The young people] talked about how [participation] can empower [children and young] people and help recovery, particularly around mental health. [They said that participation] can give people freedom…[and] confidence. Brings a lot of good out of some bad or difficult situations".*
> Participation professional feeding back on discussion with YP, CCHP YP workshop

There was also a suggestion that participation can potentially have implications for young people's longer-term health and use of services:

> *"[Y]our experience as a child and young person of health services has a massive impact on how you access services as an adult, and whether you access services or*

the impact on your health of that. It's not just about participation obviously, it is about good evidence for your clinical care together with you valuing the experience [of using services]."
Participation worker, CCHP staff and YP meeting to discuss emerging findings

It is not possible for this study to confirm that experience of health services and participation as a young person impact on use of health services and health as an adult. But this does suggest the importance of considering the long-term as well as short-term benefits and impacts of participation, both for health services and research and for young people when they go on to adult services.

How young people were credited for their involvement also created challenges in practice. It can be difficult to involve young people in research on sensitive topics, such as those which are private, stressful or *"potentially expose stigmatising or incriminating information"* (Lee, 1993, cited in Powell and Smith, 2009, p.128). The commonly cited benefit of young people gaining useful skills and experience through participation was potentially problematic in the Y-SBNT study:

"As much as I would love to put on my CV that I've been involved…people might wonder why I've been an advisor to a drug project….it just raises a few question marks….I do always have that worry that they're going to think 'Oh she was a druggie' and yes it's the truth but I don't want every employer knowing that stuff."
Y-SBNT young advisor A, phone interview

None of the Y-SBNT young advisors chose to be named in reports or other outputs, but in the CCHP study most young people were happy for their names to be included. The learning for embedding participation is to discuss with individual young people how they would like to be involved, to engage in reflective dialogue on how participation could improve and what they want to get from it.

But for many young people the benefits for their peers were more important than personal benefits, and there was often a strong altruistic motivation for participation:

"I'm involved in the [YSBNT] project so I can pass on my experience…I want to make things better…I actually don't care as much what I get out of it….I just don't want to see any other young person suffering the way I had to, or end up dead or in prison. If I can help develop something that prevents that [the Y-SBNT intervention] then I will."
Young advisor B. Telephone interview

Working flexibility and responsively

Young people moved in and out of involvement in the Y-SBNT study, and few were involved on an ongoing basis. They highlighted how it important it was to be flexible and sensitive to the needs of young people who may be vulnerable, even within the confines of a research study:

"The whole research team, the flexibility and support…has been stellar, exactly what you need when dealing with young people, and I've really enjoyed it… of course it is a research project so there is a certain amount of formality about it but [you're]

keeping it as relevant to the young person as you can which is always good "
Y-SBNT young advisor B, phone interview

Although the CCHP group started off with a fairly static group of young people involved in the strategy development workshops, this changed as the work progressed:

"Well one of the good things actually about the group [of young people involved in CCHP work] is that it is not static any more, it's constantly new [young] people coming in...and [other young] people [who] had an interest in it for a bit and then want to do something else."
Participation worker, CCHP staff and YP emerging findings meeting

In both case studies young people talked about the importance of trust and building relationships with the adults with whom they worked:

"You look for people who are, nice, polite, friendly, trustworthy, respectful. Staff who build up your trust, [who] work together to have your own say."
Young person, CCHP YP workshop

"[Participation is]...about people being...genuinely interested in you as a person as well as your views about participation...I couldn't really trust that somebody was really interested in my views about a service if I didn't feel like they were interested in me as a person." Young person, CCHP YP workshop

"I have spent the majority of my time with [public involvement lead] for this project and yes I like to think we have also built a friendship as well. That's always really good." Y-SBNT young advisor B, phone interview

"This project talks about really personal stuff and the only way I can talk openly and honestly is because I've had a chance to get to know you [public involvement lead] face to face and because I trust you. It wouldn't work otherwise .
Y-SBNT young advisor A, phone interview

'Good' participation is not always about personal relationships; this may not necessarily be possible in practice and can potentially be problematic when people leave or projects end. However the quotations above highlight how, for the young people involved in the case studies, the embedding of their participation was characterised by professionals who they felt they could trust and who were interested in them as individuals as well as in their views about services or research. This trust was particularly important for some Y-SBNT young advisors as their participation sometimes involved them talking about difficult personal experiences:

"Yeah we are young people as well so there's always that level of vulnerability and it's quite a sensitive issue...[substance misuse] is quite a shameful thing to some people...I find it very awkward to talk about it with people I don't know."
Y-SBNT young advisor A, phone interview

Vignette 3 below outlines how we worked with the Y-SBNT young advisors to embed their participation in the study, highlighting some of the issues raised above.

Vignette 3: developing participative practice with young people in the Y-SBNT study

Our work with young people in the Y-SBNT study tended focus on getting their perspectives on the current or upcoming stage of the research, partly because of the nature of the study but also because of the varied nature of young people's participation. However in addition to involving the two young advisors with the longest involvement in the drafting of the chapter on public involvement in the study report, we also sought to involve other young advisors in developing our participation practice through evaluation after meetings and by inviting them to engage with emerging learning. For example we reviewed the timing and location of the meetings when young people said that they were happy to travel, and in fact enjoyed visiting somewhere new, but wanted some time for sightseeing and social activities too. We also worked with workers from a drug and alcohol service towards the end of the project to support young people to complete application forms and attend meetings. At the young people's request these project workers also remained in the room during the last two meetings and supported young people with activities when required, as well as being some young people's nominated point of contact in between meetings.

This learning informed the development of participative practice in the study. This provided evidence of participative practice as well as being a way to demonstrate to the young people involved in the study that their feedback and ideas on how we could best involve them were not only listened to but, as far as we were able, acted on:

> *"Reading the chapter and all the findings and the work you've done, and I've done, made me feel quite special. It made me feel like my views are important".*
> Young advisor B, written feedback on draft report chapter

Involving young people in the writing up of participation in the study was a way for all of those involved to get some feedback on how their participation had informed the study, and also to contribute to the learning emerging from that participation. The Y-SBNT young advisors also informed wider guidance on young people's involvement in health research (INVOLVE, 2016d). Involving young people in reporting was key to this process and, as discussed above, was probably the closest we got to the collaborative learning that I had hoped would be central to this case study. Although the writing of the report chapter was still adult-led we were able to do this in a much more collaborative way, with young people contributing material and commenting on drafts. What the young people and I then wanted to do was to take this a step further and develop a lay summary together, as this is something over which the young people could have much more editorial control. But at the time of writing and nine months after the report was first submitted to the funders for review I was still waiting for confirmation of whether this will be possible. The

danger is that by the time we receive this confirmation the young people will have moved on or no longer be interested in being involved. While the idea of involving young people throughout the research process is often mentioned in the literature this study has highlighted how participation at the beginning and end of a research study can be difficult in practice.

[End of vignette]

11.3 Inclusion and diversity in practice

Embedding young people's participation requires consideration of how age and other aspects of social background such as race and ethnicity, disability, social class, family background and use of services *"intersect as aspects of who children are [and]…their social position* (Clavering and McLaughlin, 2010. p.604). The importance of this was illustrated by young people's participation in the Y-SBNT study, as outlined in Vignette 4 below.

Vignette 4: developing a participation model in the Y-SBNT study

The Y-SBNT study started with an established model of public involvement, an advisory group (YPAG) in which a core group of young people meet regularly and on an ongoing basis in one location (e.g. Generation R, 2016). But after our initial attempts to engage young people in this way met with limited success the research team realised that we would need to think again about how best to involve young people in the study:

> *"I can't see how that [a YPAG] was ever going to happen in retrospect. I didn't realise it beforehand but now it seems painfully obvious that that was never ever going to happen with this group [of YP] unless we change very drastically who it was that we were involving. Almost by definition the sort of [young] people we are trying to work with are not the sort of people who repeatedly turn up to meetings like these and if they did they're not the people we're working with."*
> Research team member E, Y-SBNT TMG focus group

A different model for participation emerged from reflection on the learning from the evolution of the plans for young people's participation in the study and information about young people's views on participation captured through meetings and evaluation activities. After initial analysis of this material I discussed the emerging learning with the TMG and two of the young advisors as part of the process of drafting a chapter on public involvement for the study report (Watson *et al.,* 2017). At the final young advisors meeting in November 2015 I then printed out the draft model, along with other parts of the study report chapter on public involvement and invited the young people to make additions and changes to a large print version stuck on flipcharts on the wall. This exercise then

informed the final draft of the chapter submitted to the funders. So although the model was not developed through a formal process of participative inquiry, as with the CCHP strategy, it was nonetheless developed as collaboratively as possible and drew on learning which had emerged throughout the Y-SBNT study.

Although we explored many options in the end people did not want to turn their backs completely on the YPAG idea, as young people and researchers both said that they preferred face-to-face meetings, either in groups or individually. But people also acknowledged that this may not be possible for all young people all the time. So we agreed that the best approach would be some form of ongoing group, but more flexible and young people-centred than a fixed-location YPAG with a largely static membership. The revised model (Watson *et al.,* 2017) consists of an on-going group of young people with a fairly fluid and flexible membership, alongside one-to-one and small group work which might be ongoing or one-off. Depending on the availability and interests of the young people involved this group could meet regionally (e.g. through services as point below) as well as coming together nationally (e.g. through day meetings or longer residential meetings). People were also keen that such a group would be able provide advice and support to other studies in the field and not just be linked to one project, in a similar way to many existing YPAGs. So this model is not entirely different to the YPAG idea, but rather seeks to be more, flexible, fluid and inclusive.

As a key point of learning for the study was the need to involve young people earlier in the process, in the revised model a group would be established before a project started, so that young people were able to be involved in the development of the proposal and support the recruitment of a new group of young advisors, as well as being able to be involved in other studies in the field. If possible young people involved in the initial YSBNT pilot study would be involved in recruitment through initial visits to services and through 'snowballing' via young people recruited as advisors. Young people would also be involved at all stages of the research, from proposal development to dissemination and given opportunities to be actively involved as part of the research team as well as being consulted by them. People thought that the group should be a combination of older young people (e.g. mid-late 20s) who are able to look back on their experience and, possibly more short-term and flexible participation with young people currently using services.

Given the importance of support services in engaging young advisors in the Y-SBNT study the model suggested that participation should ideally be closely linked to a few services, with an element of a public involvement budget set aside for these services to recruit and provide on-going support to young advisors as well as potentially hosting young advisors'

meetings. Parental involvement should also be considered but, given the complicated family relationships of many young people involved in the study, it may be necessary to broaden this out to other people who played an important role in young people's lives and recovery. The main role of the public involvement leads in this model would be to plan participation activity, facilitate links between young people and researchers via the services and evaluate this participation, with services taking the lead on recruitment and retention as above. All members of the research team would be allocated time to feed into, and plan for, public involvement (particularly those who are, unlike the PPI leads, directly involved in the study on a day-to-day basis).

This model sought to address many of the issues which emerged during the course of the study: the need for something more flexible and young people-centred than a fixed-location YPAG, with young people involved from the outset; a formal role for services who can support the recruitment and ongoing participation of young people who require it, but considering carefully with young people which adults they wanted to support their participation. The final aspect was for participation to be embedded in the work of the whole research team through clearly delineated roles for both adults and young people.

[End of vignette]

In the CCHP there was a perception that much of their formal participation activity focused on secondary school-age young people and did not consider the needs of younger or disabled children and young people as much as it could:

> *"There's a middle group that we're not really getting there [on a list of children less likely to be involved in participation]... we've got parents of very young children, [children with] learning difficulties and those who are harder to access but I think there's the middle group...at the top [last few years] of primary school, children [who]...are able to express themselves in what they want but maybe not in the same way [as older YP] or the systems aren't the same for them".* Health professional, CCHP staff workshop 1.1

The need for diversity was picked up early on the CCHP process by one of the young people involved:

> *"[G]ood participation involves [young] people from different backgrounds and [with] different experiences. And we [young people in group] talked a little bit about age range and...everyone who uses the services [having opportunities for participation]...because the CCHP is from 0 to 18, so it's kind of really assuring that everyone's voice is heard."*
> Participation professional feeding back for young person, CCHP YP workshop

This led to a discussion about how we might do this in practice, particularly as some of the young people who came to that first workshop did not feel very comfortable speaking in a group and had asked other young people or staff members to speak for them:

Louca-Mai: "*We've been talking about making sure that everybody's voices get heard, not just young people who might come to this group…we talked about some young people who might not feel comfortable coming to something like this [workshop] but that it's important to get their views… to look at who is and isn't having a chance to have a voice….*

Young person*: "And making it possible, yes. We really try to put ourselves into other [young] people's shoes as well when we're doing [Young People Friendly] assessments, like what experiences are like for other [young] people as well, for different age groups".*
CCHP YP workshop

The young person's comment above raises some interesting points about representativeness. It can be assumed young people only represent themselves and so any group or other participation activity needs to be as diverse as possible to have value:

> *"I had this image that it would be good to go to a meeting and have at least 8 or 10 young people…because the problem is that if you have one or two people then they might have very particular views…you wonder to what extent the advice you get is not as helpful as if you've got a larger group. I remember coming down to London and hoping that we had that [larger group] and then we had two [young] people there and feeling quite deflated about it…[although] we had a good discussion.*
> Y-SBNT team member A. TMG focus group

But the young person quoted above is articulating a rather different perspective: that young people with experience of participation can put themselves in other's shoes. Even if their personal experience is different they will be closer to other young people's experience than most adults especially if, as in the case of the Y-SBNT study, the young person has considerable experience as a user of the service(s) in question. However this study also found that it was important for young people to have some relatable experience, e.g. as users of CCHP or substance misuse services respectively. While 'representativeness' can be a subject for debate (e.g. Cairns, 2006; Ocloo and Matthews, 2016) it was considered to be important by several CCHP participants that participation reflected in some way the service user population of services:

> *"[The] area that [our service is] in [has] a very high ethnic mix… [so] I would also like for us to be thinking about how we involve the BME community in [participation] as well. Because we do have some pockets of our services that struggle to get engagement [with BME communities], and this kind of thing [participation strategy] might be something that is really powerful in enabling us to have better engagement".* Health professional, CCHP staff workshop 1.1

This suggests that more inclusive participation and more inclusive services can be synonymous.

The participation of young disabled people, and particularly those who don't use speech, was also mentioned in the CCHP. Although not a primary focus for this study it is nonetheless an important consideration in the context of inclusive participation in practice, particularly in relation to health services, given that young disabled people are

considerably less likely than their non-disabled peers to be involved in decisions about their own care and about service development (Franklin and Sloper, 2009):

> *"So it might be about adapting it [information about participation for children using CCHP services]. Say for example…if it was a child who didn't have verbal communication or couldn't read and write, we could then adapt it so it's more visual…they should definitely have the same rights, but we just how adapt the way that we present the information."* Health professional, CCHP Staff and YP workshop 1.4

But other participants questioned the assumptions being made about children and young people's capacity to communicate:

> Participation professional: *"[You need to be]…asking some basic things [about what] assumptions you're making…testing the ground all the time with what that young person's capability is…*
>
> Health professional: *"Yes, there are some pilots going on…with children and young people with quite severe learning difficulties, ways that they can communicate…around planning for the future for themselves".*
> *C*CHP staff workshop 1.1

The awareness of alternative means of communication is important, and indicates the flexibility and young person-centred working that emerged as so important to successful participation in both case studies. These discussions also raise the issue that the normative impacts of a 'child first' homogenous view of children and children's rights can unintentionally marginalise young disabled people (Curran and Runswick-Cole, 2014). For some children and young people using CCHP services support from parents or carers might have been a key factor in making participation possible. But others, as with some of the young people involved in the Y-SBNT study, their family could make it harder for them to engage with services in the first place, which needs to happen before participation is even possible:

> *"[Children who]…through no fault of their own, chaotic parenting or whatever, they don't come to appointments. They're excluded or not in school so we have no contact with them. Young children who don't understand the importance of whatever appointment they've been invited to and [have] parents who are unable to meet their needs…How do we engage them? They're always our big challenge but what we find is that they don't come to two appointments and then they get told that they're now not on the waiting list anymore. What can we do about that?"*
> Health professional, CCHP staff workshop 1.1

But adult assumptions about who can and cannot participate were challenged in both case studies:

> *"[S]ometimes we underestimate a young people's capacity to participate and that could be disempowering without meaning to be….we might think that young people might not be in the right place or aren't ready to participate…when actually those might be the times that…they really need to and [participation could] enable them to take some responsibility about their health."*
> Participation professional. CCHP staff workshop 1.2

> *"Some professionals [in substance misuse services] don't see the value of these projects and don't commit to recruiting young people. Without this you just can't engage young people and do projects like this [YP's participation in Y-SBNT]".* Y-SBNT young advisor B, feedback on draft chapter

This study found that young people are far from a homogenous group and that taking into consideration their age, background, experiences and living circumstances was essential to embedding participation effectively in both the CCHP and the Y-SBNT study. In both it was not a case of who could or could not participate, but rather how participation could be developed in ways that worked for the young people concerned. The challenge is that young people's participation in health services and research still tends to focus on adult-initiated participation within a formal setting. However the learning from this study suggests that formal structures such as forums or advisory groups are not necessarily always the best ways in involve children and young people, and may actively exclude those who are less frequently heard.

11.4 Developing practice and building capacity

11.4.1 Participation in organisational policies and processes

Young people's participation in the Y-SBNT study was not just about their involvement in the research process but also in the development of an intervention, a key output of which was a practice manual for services. This raised some interesting issues about how young people's involvement in health research is reflected in the policy and practice which that research aims to inform, as well as in documents relating to the research process:

> Research team member 1:*"…one of the very concrete things [young people contributed to the study was]…their input into the leaflet for example….that was a very specific thing they gave lots of comments which we incorporated…*
>
> Research team member 2: *Yes definitely their input was really good. It's only through showing it to the people you're targeting especially that you can get concrete feedback about it and I thought the suggestions of wording and layout, the order, it was actually very useful…*
>
> Participation lead: "*You said something similar when you worked with [one YP] but also other young people in terms of the questionnaires and you also raised [how YP] help[ed] with the various iterations of the interview guide as well …*
>
> Research team member 3: *"I think the [open] letter [used in training materials for practitioners] that [one YP] wrote was a good indication of how difficult family dynamics could be and it was an eye opener to the sort of things we might expect in young people's lives. So I thought that was really good and really good of [YP] to share that [information about her personal experience]. Also, there was a time when [members of research team] were doing the training and the [pilot location] therapists had a query about…[content] in one of the [work]sheets, and when you showed it to the young people…[their feedback] really helped to formulate something concrete".* Y-SBNT TMG focus group

The exchange illustrates how participation informed materials used by practitioners working with young people in the study's two pilot sites. But it is interesting that what the researchers in the conversation above seemed to most value is feedback which was 'concrete', so young people commenting on research tools and other materials. The summary of young people's contributions produced for the study report (Appendix 13) also focused on detailing on specific aspects of the study. It is of course important for young people as well as professionals to see how participation leads to demonstrable outcomes, but a focus on concrete outputs can focus participation to young people responding to adult-led materials rather than a more collaborative participation.

There have been repeated calls to involve patients and members of the public in healthcare improvement in response to serious clinical and service failings in the UK and internationally (Ocloo and Matthews, 2016). In CCHP the integration of participation into organisational policies and processes was seen as an important element in meeting statutory requirements around patient safety:

> *"We have got an advice and complaints procedure [which we included in the participation mapping]…around the context of things like the North Stafford enquiry - where the government is now expecting us, and rightly so, to be listening to things that our patients in that context are telling us…So that is quite important that we respond to that."* Health professional, CCHP staff workshop 1.1

As well as the inclusion of participation at a strategic level on policies and documents, it was also felt to be important for the strategy to be tied into 'complaints, compliments and concerns' processes and to inform opportunities for individual-level participation:

> Health professional 1: *"We were just thinking about whether we would be want to ask the child questions… [in the] initial assessment review… to include on our paperwork, so it's there in black and white…*
>
> Health professional 2: *"…yes but we don't always document…when we should be asking the child [their views]".* CCHP staff workshop 2.1

This discussion about the importance of including a space to record children and young people's views in the documents and policies used in everyday clinical practice highlights how it is still standard practice in healthcare settings to seek the views of parents or carers instead of, rather than as well as, the child. But, as discussed in 2.3.1 adults can impose their own perspectives, consciously or unconsciously, on young people or have different perspectives on what is in the young person's best interests (Ehrich *et al.*, 2015). If the child's views are seen as less important, or less valid, than adults' views this will influence practices and approaches towards them. If the first document a health professional picks up when they see a child or young person for an initial assessment requires them to consider the child or young person's views when planning their treatment that is an important step towards embedding participation. By seeking to ensure that they consult

children and young people as well as parents about their needs and expectations of a service, health professionals will hopefully then develop the confidence to involve young people in service design and delivery.

11.4.2 Demonstrating a commitment to participation

In the previous chapter I discussed how the embedding of participation requires a commitment that is shared and understood by managers, practitioners and young people as well as by commissioners, regulators and other external bodies. When considering how this could translate into participative practice in the CCHP the focus was on raising awareness, sharing learning and celebrating success:

> *"I was wondering whether we could get the information about participation to everyone in the CCHP regularly so that people know what's going on… It's there for [participation workers] all the time but for other people…they hear about it and then it's gone and it's about raising the profile [of participation] and keeping it there."*
> Participation worker, CCHP staff and YP workshop 1.4

In addition to raising awareness and sharing learning there was also an acknowledgement of the importance of documenting what was happening and avoiding duplication in a complex and diverse organisation:

> *"The reason I wanted to join to the [participation strategy] group is because when we went to [a recent] awayday it became very evident that loads of people are doing really good work, but it wasn't being recorded, and nobody…seemed to know what anybody else was doing… so I just wanted to get involved in pulling it all together."*
> Health professional, CCHP staff workshop 1.1

Demonstrating a commitment to participation involved publicising how young people were involved to other children and young people who are current or potential users of the organisation's services, as well as to staff and current or potential partners. Young people were supported by Barnardo's to produce their own material to publicise the organisation's commitment to participation to current and potential users of CCHP services (see 10.2.3). They also contributed to internally-focused materials such as project newsletters and the cover letter for the strategy discussed above, and externally–focused materials including a blog post (Hathway, 2014) and film (CCHP, 2015a).

In the Y-SBNT study there were three main ways in which young advisors contributed to communications: to the research team and TMG, to services and young people participating in the study and as young advisors and to external audiences. In relation to internal communication young people contributed to documents such as the project newsletters and PPI plans (Appendices 11 and 12). However as outlined in Vignette 3 above this did not happen as much as I would have liked due to the varying nature of young people's participation in the study, which made it difficult to regularly involve young people in reflecting on how they had been involved. In the second area young advisors

contributed to the development of study recruitment materials aimed at young people, and training and other materials for staff in the services piloting the intervention as discussed above. Young people's participation in the third area, external dissemination, was particularly important to the Y-SBNT study, given that one of the study's objectives was:

> *"To explore and develop models of patient and public involvement which support the involvement of young people in a study of this nature."* (Copello, 2014, p.15).

Young advisors contributed extensively to, and co-wrote elements of the chapter on young people's participation in the study report submitted to the funders in January 2016. Prior to this one young advisor co-presented a paper at the NIHR INVOLVE 2014 conference on young people's involvement (Brady, Templeton and young co-presenter, 2014), and two young advisors contributed to an article on emerging lessons on young people's participation in the Y-SBNT study for an INVOLVE newsletter focused on young people's involvement in health research (Brady, Templeton and young co-authors, 2015).

The work we did in the CCHP on embedding children and young people's participation was also publicised externally through the young people's film (CCHP, 2015a) and a research summary (Appendix 8) which was launched at the 2015 NHS Expo in a workshop I facilitated with the Barnardo's participation manager and a two CCHP colleagues (Brady *et al.*, 2015). In both case studies this externally-focused information sharing was potentially important for raising the profile of the organisation or team involved, making links and hopefully securing future funding:

> *"We are not doing [participation] for the commissioners, but when I do go and meet with them and I say 'look at all this great feedback [from children and families]' their confidence in the service that they are paying for…you can see it physically growing and when you can tell them…there's these nuggets of things that are difficult, their confidence grows again… I think in terms of how we treat children and young people that does mean a big thing for our future."*
> Health professional, CCHP staff and YP meeting to discuss emerging findings

In both case studies demonstrating a commitment to participation was about being honest and open about challenges as well as celebrating successes. A culture of shared learning can hopefully have practical benefits for embedding participation both internally (sharing and replicating good practice) and externally (for example in relation to the commissioning of future services or research).

11.4.3 Partnership working

This study found that it was important to draw on the expertise of the voluntary and community sector but also of young people with prior experience of participation. The role of the voluntary sector was key to the successful participation of young people in the Y-

SBNT. The young advisors also felt that this would be the best way to get young people involved in future studies:

> *"You need to go out to more substance misuse services and say 'can you help us…can you provide us with [access to] young people if they are interested?' and explore different avenues. Put the word out: maybe get a day with a drug and alcohol service…just introduce the project and give them more information about what we're doing and what we want to do, and seeing if they are interested….you could see if you can talk to some young people while you're there. Then you can give them the options of just having a chat or getting more involved, but with no rush and no pressure…just get them to talk to you".* Young advisor A, telephone interview

> *"The idea of involvement being linked closely to a few [substance misuse] services was seen as important [to young people]. For example some of us would probably have been unlikely to attend this meeting without support from staff".*
> Feedback from young advisors' meeting, April 2015, on what future involvement could look like.

The proposed new model of participation for a future study (Vignette 4 above) includes a role for substance misuse services as partners to support young people's participation. However not all young people would have positive or ongoing relationships with services, or be happy with support staff being in the room during meetings. It would therefore be important to work with young people to find out what worked best for them which may, or may not, involve ongoing support from services.

In addition to the importance of partnership working within and across the whole range of NHS services provided by CCHP, partnership with the voluntary sector has been at the heart of the organisation from the outset. Barnardo's role within the partnership was to work with CCHP services to:

> *"…support children and families to have a say, recognising them as experts in their own lives so they can influence how their health services are delivered".*
> (CCHP, 2015b).

This role was seen as central to both the ethos of the CCHP and the future development of participation in its services:

> *"I know from seeing this partnership from the very beginning…that the successes we have had…have been when it has been a true collaboration between us [Barnardo's] and the CCHP [NHS services]…I want to feel like we are building on that and that [collaborative working] becomes more of an expectation for everything that we do, because we have got so many examples now of how that has made such an impact for services and families".* Participation professional, CCHP staff workshop 1.1

As a community health partnership, the CCHP also worked closely with schools and this was acknowledged as a potential source of collaboration for strategic and individual participation:

> *"There's a lot of work going on about person-centred planning, integrated education and health care plans…the family and the young person being very much more involved in their plans for the future,…but it's also for their statement of education."*
> Health Professional, CCHP staff workshop 1.2

In addition to working in partnership with other professionals and young people, there was discussion about working in partnership with families:

> *"[It's] not only learning from each other as professionals but learning from the families, I mean we have learnt so much…from our families and obviously they have learnt so much from the systems and they have got more idea really about how systems work. So it is about supporting each other."*
> Health Professional, CCHP staff workshop 1.2

The idea of partnership working often refers to relationships between organisations (i.e. NHS/academic and voluntary sector or between health, social care and education services) or between adults and young people. But the more complex ideas of partnership encompassing all these elements, along with significant adults in young people's lives, suggests the importance of participation taking place in the context of children and young people's whole lives (Percy-Smith, 2016), particularly given the transitory nature of many children and young people's contact with health services.

11.5 We know what we do but we need to show how we do it: evidencing participation

In order to engage in critical appraisal of participation it is necessary to be able to assess the extent, quality and impact of that participation (Lansdown, 2004) and:

> *"…in an age focused on evidence-based practice as a key determinant of funding and government support…the need for evidence about the impact of children and young people's participation is becoming ever more urgent"*
> (Crowley and Skeels, 2010, p.184).

Despite the increasing interest in public involvement in health research, there is as yet relatively little robust evidence about its impact (Brett *et al.*, 2014) and even less on the impact as a result of young people's participation (Fleming, 2010):

> *"[W]e know that we do [participation] but we need to demonstrate that we do it and we need to find a way of making sure that everybody does it in a similar way".*
> Health professional, CCHP staff workshop 1.1

> *"Participation needs to be based on a challenge and a need and a desire to learn from each other, especially from children and young people, and to be able to measure that learning so that you understand what your potential is and…that potential is always moving."* Participation professional, CCHP staff workshop 1.1

The participation strategy and framework were seen as instrumental to measuring the extent of, and learning from, participation in the CCHP as well as creating the culture in which it could happen:

> *"I think one of the values [in the participation strategy] will be about the measurement of success, and placing value on effectiveness… because that is a way of bringing in lots of indicators around what does success mean?"*
> Participation professional, CCHP staff workshop 1.2

But CCHP participants stressed the importance of fitting in with the many other existing ways in which health services have to measure impact and outcomes in relation to participation, inclusion and engagement:

> *"Even though you've done Young People Friendly… [which] does have an action plan…this document [the participation framework] will support your [YPF] action plan because it will help you feel like you are being smart, that it is achievable, that it is time-limited, that it is reviewable…and that you are not having something that's too onerous. I think some other services' Young People Friendly Action plans…are slightly out of control I think in terms of what they're expecting of themselves. I can't quite believe I'm saying that but people have got too many participation actions".*
> Participation professional, CCHP staff and emerging findings meeting

In the Y-SBNT study it was relatively straightforward to assess the impact of young people's participation on the study. This was partly because it was a smaller, time-limited project but also because the reporting requirements for NIHR-funded studies required us to keep records and regularly update on public involvement:

> *"[W]e've done an awful lot of work trying to engage [young] people and consult [them] in various ways [during the Y-SBNT study]…I think once we've put all that together, and we learn from it, some of that could be communicated to others…[as well as] what they did in terms of [informing] the [Y-SBNT] intervention".*
> Research team member A, Y-SBNT TMG focus group

Measuring the extent, quality and impact of participation was important to convince internally as well as externally:

> *"For people to buy into [participation] you have to see the closed feedback loop… the consultation is done, viewpoints are expressed, they are taken seriously and then there's going to be a benefit to clinical services for [children and] young people. If you can see that process, as a clinician I think you can buy into things…someone who was in a meeting I was in…said 'actually where is the evidence that participation improves clinical services?'."*
> Health professional, CCHP staff and YP emerging findings meeting

To be meaningful participation needed to make a difference to services as well as for children and young people:

> *"[Participation]…needs to result in change of some sort, whether that be…a physical thing, a change for that [child or young] person, a change for in the way they feel about it [the service, their condition] or whether they felt like they've been listened to even if you can't act on it".*
> Participation professional feeding back on discussion with YP, CCHP YP workshop

> *"We need real examples about how [participation is] affecting [children and young] people's lives and how it changes their lives…I think that's the powerful part rather than it being just something [services] need to do….So, this is what we do and this is how it feels and this is how it's benefitting [children]".*
> Health professional, CCHP staff and YP workshop 1.4

It may be that young people participate in a service evaluation or other activity and agree that nothing needs to change, or indeed take part in participation which does not have any major transformative effect on their lives. Changes may not be big or dramatic but in order

to embed participation the practice of participation needs to stem from a culture in which such change is possible, and also that any change (or indeed a need for things to continue as they are) is evidenced and documented.

> *"There is no point us getting [any of] that information if we're not going to do anything about it…it is [also] about really being committed to try to change things."* Health professional, CCHP staff workshop 2.1

Critical appraisal of participation in this study was about a wider concept of assessment rather than a narrow quantitative measurement of success. It was about documenting when, where and how participation was happening, as well as what difference it was making to children and young people and to practice.

11.6 Whose agenda?

Young people's participation in both case studies took a variety of forms at different times. But participation was still conceptualised primarily as being about young people being *"expected to fit into institutional contexts, in an adult-driven framework"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.11). But:

> *"Real participation does involve a transfer of power to children. Achieving that transfer can only be achieved by the introduction of legal rights, means of redress and wide-ranging cultural change towards respect for children as rights holders, entitled to active participation in all the decisions that impact on their lives.".* (Lansdown, 2010, p.22).

The predominant culture in many health services and research studies is still one which emphasises young people's vulnerability and does not necessarily translate the concept of participation into a transfer of power and choice (McNeish, 1999), and that was reinforced by this study. But participation is not just about listening, or 'voice' but about shared action (Nolas, 2015; Percy-Smith and Thomas, 2010).

This chapter has explored how both case studies were trying to move towards more young person-centred participation. The flexibility in the Y-SBNT study meant that the boundaries between individual and collective participation were quite fluid. But, as with much public involvement in health research, it was an adult-led set up in which the focus for participation were established before young people became involved:

> *" [W]e're expecting [young] people to somehow come in [to an adult-initiated meeting] and engage with us and maybe they take one look at it and think 'I'm not interested in this', or they're interested for a bit but then you know it takes time [to get and keep them engaged]. We are almost expecting too much from [young] people."* Research team member B, Y-SBNT TMG focus group

We were expecting young people to get involved in a research project set up and run by adults, at a meeting organised by adults, often in an adult space such as a university. It is not so much that the adult researchers were expecting *"too much"* from young people but

rather that we had started by thinking about participation in terms of how it could best inform the research, rather than starting with the young people we wanted to involve and how participation could work best for them. The young people themselves were very clear why they should be involved:

> *"...because it is about us... we know about the services and how to make them better. We are the people they [services] are meant to be working for".*
> Young advisor at last Y-SBNT young advisors meeting

In the CCHP participation activity had tended in the past to focus on activities like young people's participation in recruitment and training, as well as supporting young people to give feedback on existing services. But it was acknowledged that they still had little power or control over how those services were delivered:

> *"If we're [looking at]...what services are needed...this is currently decided area by area...[but] at what stage are we gathering feedback from families? So, for example when there's a programme for autism...that could vary area by area across the partnership and at what point are parents and young people consulted about whether that programme is working, or what's right for them?"* Health Professional, CCHP staff workshop 1.2

> *"What we generally don't do [is say] 'if we had a magic wand and we could provide you with a health service, what would you want it to be?' So, we ask them what they think of something that we've already come up with the idea for, but we don't necessarily ask them for the idea."* Health professional, CCHP staff workshop 2.2

For some participants this was challenging, especially in circumstances in which difficult decisions had to be made:

> *"Children and young people and families need to be part of decisions that we make, but only when we felt they're appropriate...obviously not everyone can make decisions about everything...children and young people and families need to be realistic within the constraints and resources of the service...I think this is part of where we've maybe gone wrong in the past [is that] expectations are very high, so it's almost like managing expectations".* Health professional, CCHP staff workshop 2.2

> *"Managers might decide that...for savings we're going to cut X amount of jobs... should....children and young people and families be part of that decision-making or not? Or...if we're not offering [a service] anymore at a particular venue because we don't have the staff...I'm not sure that necessarily children and young people and families can make that particular decision. So it has to be...when we can involve them appropriately, doesn't it?"* Health professional, CCHP staff workshop 2.2

While it is certainly true that there are dangers in over-promising in participation, there is some interesting language in the quotations above which suggests that, for all the CCHP's commitment to participation, young people were still very much *"expected to fit into institutional contexts, in an adult-driven framework"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.11). But there was an awareness of this:

> *"... all human beings have a right to be heard in decisions that affect them. And for anything in terms of, say, a change of service or cutting services, there is a consultation process, so [children and young] people should be given the opportunity to give their view and know something is happening before and for that feedback to*

> *be understood and responded to. [The organisation may] look at it and say 'yes this is a really valuable resource but we've got no other option. It would mean cutting something which is even more valuable'. But that [consultation] process is gone through."* Participation worker, CCHP staff workshop 2.2

Although consultation is not the same as a collaborative process of shared decision-making (see 2.2.1) it is at least an opportunity for the views of children, young people and their families to inform these difficult decisions. Participation of young people in service improvement through feedback on their experiences, along with actively seeking that feedback and committing to acting on it, is a step towards shared decision-making if not a transfer of power.

In terms of young people's power and control in individual participation in the CCHP there was a way to go:

> *"[A clinician talked about]…how to strengthen children's capacities to take increasing levels of responsibility for their own health and development…some services don't do it so well, and inadvertently disempower parents and children by going in and doing to rather than working with [children]… it's actually getting much better through things like goal setting, but there's still work to be done".*
> Health practitioner, CCHP staff workshop 2.2

The above quotation highlights the potential personal benefits to children and young people of individual participation in health services, that they then have more power and control in relation to their own health. But it highlights how some clinical practitioners may inadvertently disempower children and young people:

> *"[I]t's about your [young people's] relationship with the service, it's about the role you play in the service, it's about…your expectation, not of what the detail of what [a service] is going to offer, but how that is communicated, how you were included in that process."* Participation professional, CCHP staff workshop 2.2

While some practitioners were worried about services being *"robust enough to be able to handle very empowered parents and children"* (Health professional, CCHP staff workshop 2.2) others pointed out that:

> *"[W]e need to recognise that children and young people are going to find it hard to give their feedback, especially if it's not positive….But the more they feel like you're serious about what you think the more they're likely to trust you and actually say it."*
> Participation professional, CCHP staff workshop 1.2

So some young people may need support to feel comfortable giving critical feedback, but services may also need support to take that feedback on board.

In both case studies we wanted to involve young people because of their experience: of participation: in community health services in the case of the CCHP and of substance misuse services in the case of the Y-SBNT study:

> *"We talked about being recognised as…the experts in being young people who use [services] and actually being listened to and the suggestions actually making changes*

within a service".
Participation worker feeding back on discussions with YP, CCHP YP workshop

"What we want is their lived experience isn't it? I don't need them to tell me how to run a randomised control trial, I know that…We want them to be right in the middle of what we want to do…why what we're doing will or won't work [with YP using substance misuse services.]" Research team member B, Y-SBNT TMG focus group

In the Y-SBNT study services proved to be both barriers to, and enablers of, young people's participation. It was sometimes difficult to engage the interest of services in the potential opportunities participation could provide for young people.

"Some professionals don't see the value of these projects and don't commit to recruiting young people. Without this you just can't engage young people and do projects like this". Y-SBNT young advisor B

Some services were reluctant to pass information onto young people because they were concerned about young people being too vulnerable or, conversely, because they thought that young people might not be 'academic' or reliable enough. The young people who did get involved in the project felt it was important to emphasise that the experiences which may have made them vulnerable were the often the reason why they wanted to be involved and that academic ability was not a requirement for involvement:

"[Tell young people that] you don't have to be a scientist, you don't have to be a genius, all you have to do is have experience of using these services and that's the skill [required]" YSBNT young advisor A, telephone interview

Embedding participation in practice involved an awareness of barriers and obstacles which may be created by adults who have power and control over young people's access to participation opportunities. But there is within this an assumption that a perceived lack of diversity in young people involved in formal participation activity is due to lack of opportunities, access or information. But another question to consider in relation to who does and does not get involved is whether all children and young people are interested in participation? As well as having a right to have a say in matters which affect them (UN, 1989) young people have the right to choose whether or not to participate. Individuals who may be under significant stress might for example see limited personal benefit to being involved as a research collaborator (Beresford, 2000).

In addition to issues of complex lives as discussed above, the Y-SBNT study had the challenge of trying to identify young people who had used substance misuse services in the past but were now in a position to reflect back on their experience. Feedback from services suggests that many young people who fit this description may have either moved on and no longer be in contact with services, not wish to look back on a difficult period in their lives or have relapsed. Young people with complex needs, especially if they are living in care or in crisis, as was the case for many of the young people involved in the Y-SBNT study, may feel powerless about decisions affecting their life and find it difficult to actively

say 'no' to participation, instead opting out by remaining silent or not responding to contact (Waldman, 2005). This was certainly the case with the Y-SBNT study as, despite various attempts to get feedback from young people involved early on in the project, all the young people who opted out of further participation did so by not responding to contact rather than actively opting out. There was a difficult balance to be struck between keeping in contact and leaving the door open and not making young people feel 'hassled', especially as many were still using services and being contacted regularly by professionals about appointments and commitments. So, after a few attempts at contact we normally sent young people a final message saying that as we had not heard from them we would assume they were no longer able to be involved in the project, but that the door was always open if this changed at any point. During the course of the study no young person responded to say they would like to get involved again, or to give us any feedback on why they were longer engaged.

11.7 Conclusions

This chapter explored how people worked within and beyond the culture, structure and systems outlined in the preceding three chapters. Translating the rhetoric of participation into reality in the CCHP faced challenges when faced with the realities of clinical practice and the need for more to be done to address issues of diversity and inclusive practice. Addressing these challenges required the creation of opportunities for shared learning in relation to both individual and strategic participation, and tools and practical support to develop both practitioners' and young people's confidence. Young people involved in both case studies spoke about the benefits of participation for their wider peer group, as well as the personal benefits of being able to use sometimes difficult personal experiences to create positive change.

Cultural tensions between medical models of treatment and participation create challenges to embedding participation within the structures and systems of health services and research, and when faced with the realities of professional practice. Embedding participation in healthcare interactions and research processes requires professionals to have a good understanding of participation as well as their professional responsibilities. To be embedded participation needs to be an integral part of routine processes such as training, supervision and team meetings, as well as being included in documents and policies used in everyday practice. This is about more than just getting people to fill out a participation framework or contribute to a public involvement plan. Internal and external dissemination is key in both building a culture and demonstrating a commitment to participation, as is drawing on the expertise of young people and organisations who work

with them. Critical appraisal of participation is about documenting when, where and how participation is happening, as well as what difference it was making to young people and to practice. Both need to be consistently evidenced in some form in order for participation to be shared, improved and embedded. This evidence also needs to be integrated into existing systems and processes as much possible, and be part of a wider learning culture.

There is still a long way to towards more young person-centred participation in health services and research, and issues of power and control emerged in both case studies. These are key issues to be discussed in the next and final chapter in this thesis, which brings together the findings discussed in the last four chapters with the theoretical and policy background, epistemology and methodology outlined in Chapters 2 to 5.

12. Discussion

12.1 Introduction

This chapter concludes this thesis and draws together the learning from the inquiry into embedding young people's participation in health services and research. I consider the limitations and weaknesses of this study and the contribution this thesis is making. The framework in 12.3 summarises this contribution by synthesising the core elements which this study found were necessary to embed young people's participation. In then go on to make recommendations for future research which would build on this thesis or investigate issues which I was unable to pursue within this study.

This study sought to understand how organisational culture, systems and practice support or create barriers to young people's participation, and to locate this within a framework of participatory, rights-based research (Boyden and Ennew, 1997; Beazley and Ennew, 2006). The research approach was underpinned by a theoretical framework, outlined in 2.5, through which I sought to engage in practical and collaborative inquiry within a participatory paradigm (Heron and Reason, 1997) in two case studies. By working with two case studies, a community children's health partnership and a randomised controlled feasibility trial, I explored how participation was understood and built capacity through learning with the aim of informing the embedding of participation. The study drew particularly on the literature on children's rights, participation, childhood studies, health studies, and public involvement, touching also on disability studies, youth work and social policy more broadly.

This study set out to investigate how people conceptualised young people's participation, the reality of how these understandings of participation were operationalised and the barriers and challenges faced when attempting to embed participation in practice. As the starting point for an action research-informed inquiry these questions *"cut across and introduce[d] the possibilities for change on multiple levels"* (Herr and Anderson, 2015, p.91). They therefore represented a starting point for a participative inquiry with two case studies, and I now turn my attention to the learning which emerged from this process of inquiry.

12.2 Embedding young people's participation in health services and research: key points of learning

12.2.1 Understandings of participation

Defining participation

Participation is now generally accepted as a 'good thing' especially in services working with children and young people (e.g. Sinclair and Franklin, 2000; Kirby *et al.*, 2003; Percy-Smith and Thomas 2010), and in research about children and young people (e.g. Clavering and McLaughlin, 2010; Roberts, 2000; Shaw, Brady and Davey, 2011). But what is meant by 'participation' is often contested (Lansdown, 2006) and terminology, typologies and models (e.g. Hart, 1992 and 2008; McNeish, 1999; Wright *et al.*, 2006) can be contradictory and opaque (Boyden and Ennew, 1997; Kirby *et al.*, 2003). In order to understand what it was we were seeking to embed, this study explored how adults and young people conceptualised participation and whether establishing a shared understanding of participation supported the embedding of participation in culture, systems and practice.

The definition of participation which emerged from my work with the CCHP (see 8.1) is of participation is a process and culture in which children and young people are listened to, their opinions respected and they are actively involved in decision making which brings about change in themselves, their peers, the services they use and their communities. But while this definition acknowledges the importance of culture as well as process and implies a more active form of participation than just listening to children and young people's views, it still implies that the scope for their influence is largely determined and controlled by adults (Boyden and Ennew, 1997), which this study found to still be the norm in both health services and health research. It does not imply a fundamental change in the relationships between young people and service providers (Davis, 2011). I think that, in seeking a more participatory, inclusive and socially-just understanding of participation in practice (Todd, 2012) this definition could go further. Of course children and young people should be listened to, have their views respected and acted on and be actively involved in meaningful and effective decision-making, but within this definition is an implicit implication that it is adults who hold the power. It is they who do the asking, the listening and have the power to put into practice (or not) decisions which children and young people are involved in making. The working definition for young people's participation in the Y-SBNT study was the NIHR INVOLVE description of public involvement as: *"research…carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"* (INVOLVE, 2016a). The extent to which this participation is active, authentic and ongoing depends on how researchers choose to interpret this definition, but as with the

CCHP definition it is not explicitly about shared action and power, and only alludes to participation in which young people contribute *"on their own terms and of their own volition…[rather than being] expected to fit into adult ways of participating"* (Cockburn, 2005, p.116) . It may be that that such participation is not yet possible in many health services or clinical research studies but it is certainly something that this study sought to challenge and explore.

Many participation toolkits and handbooks (e.g. Wright *et al*., 2006, Kirby *et al.*, 2003) clarify the meaning of participation principally in relation to the context in which they have employed it (i.e. state their working definition of participation). However this study identified a lack of information on how participation was understood by those who work with children and young people, or how these understandings may affect participation cultures and practice. No definition is all-encompassing and this study did not aim to come up with a 'new and improved' definition of participation, but rather to develop a shared understanding of what it was we were trying to embed in the case studies, and the values which underpinned this. In the CCHP conceptualising participation based on established definitions and practice was the first stage of the learning process. In the Y-SBNT study learning from practice brought recognition that the way in which participation had originally been conceptualised did not necessarily work for the young people we were seeking to engage. This study found that understandings of participation cannot be taken for granted but need to be developed and reviewed, in collaboration with children and young people, in light of experience and the context in which participation is taking place. Understandings of participation inform culture and practice, and exploring these understandings can help to move away from ideas of primarily top-down participation which focus on 'listening to' and consulting children and young people (Davis and Smith, 2012) towards a more nuanced and authentic participatory practice in which young people are directly involved in decision-making and co-production (Hill *et al*., 2004; Shier, 2001, Todd, 2012), through processes of collaborative learning, dialogue and inquiry.

Individual, strategic and collective participation

The conceptualisation of participation in this study incorporated two key dimensions: individual and strategic, concerned with *what* young people are involved in; and individual and collective: concerned with *how* young people are involved. The study found that considering how young people are involved is as important as what they are involved in, particularly when seeking to embed more inclusive and socially-just participatory practice (Todd, 2012). However these are not distinct dimensions, and indeed this study found that it is helpful if the boundaries between them are flexible to enable young people to move

between levels and types of participation at different points, as well as to develop participation practice which works effectively within organisational cultures, systems and processes. For some young people individual participation is a way to build their capacity to be involved in more strategic or collective participation, for others participation at a strategic level enables them to gain confidence to have a say on an individual level.

Typologies and models of participation often focus on adult-initiated, context-specific participation within a formal setting (Davis and Hill, 2006; Malone and Hartung, 2010) and the dominant structures for strategic participation in the UK are often formal groups such as youth councils, forums and advisory groups (Crowley, 2015). In both case studies this was very much the case and considering individual and collective, as well as individual and strategic, participation has implications for who is and is not included in participation as well as for adult-child power relations. Young people may indeed need support and encouragement to be involved in strategic participation, but suggesting that they need to be 'empowered' to have a voice in adult decision-making processes and require specific knowledge, experience and skills implies that young people need to adapt to adult ways of working rather than adult professionals developing more collaborative and authentic participatory practice. The distinctions between individual, strategic and collective participation are also adult constructs and, while important in participation theory and practice, are not necessarily meaningful or important distinctions for children and young people. 'Empowerment' was used by study participants to describe a process in which power is given by someone (adult/professional) who has it to someone who does not (young person) but also, by a young person, to mean the ability of the individual young person to take control of their situation rather than professionals doing so. Both understandings are important, as is awareness that how participation is conceptualised has implications for how it is practiced and how it can be embedded.

12.2.2 Cultures of participation

Defining 'culture'

As well as understanding how participation is conceptualised, there is a need for greater understanding of how institutional and socio-cultural contexts inform the application of different typologies of participation (Tisdall *et al*., 2014), how cultures inform participation in practice. A culture of participation is the ethos of an organisation, shared by professionals and young people, in which participation is seen as a wider concept than just specific events or activities (Kirby *et al.*, 2003; Wright *et al.*, 2006). A culture of participation was described by study participants as a process and a journey, as well as a set of shared values that inform practice. But in practice defining the 'culture' of the case

studies was less straightforward than the Kirby *et al.* (2003) and Wright *et al.* (2006) definitions suggest. In the CCHP culture was something fluid and amorphous which varied within and between services, professional groups and geographical areas as well as the wider NHS. This raised questions about whether and how professionals identified as being part of a larger organisation rather that the specific service in which they worked, and how far a complex and geographically spread out organisation like CCHP could be said to have a culture. It was therefore important to understand professional identities as well as organisational structures and decision-making processes before deciding on the best way to embed participation. My work with the CCHP was essentially about building on and embedding a participative culture which was a core part of the ethos of the organisation, as well as addressing cultural tensions between medical models of treatment and the language of participation and children's rights. By contrast work in the Y-SBNT study was more about trying to establish a culture of participation within the wider framework of public involvement in health research. These cultures need to be understood in the relation to the institutions which commission and manage health services and research and the structures and systems which support this.

While it was important for participation to be part of everyday practice, this study found that it can be embedded in an organisation or project as a parallel process rather than being wholly integrated. Indeed in both case studies there were advantages to doing so, for example Barnardo's role in CCHP as a 'critical friend' without responsibility for the delivery of clinical services, and my role in the Y-SBNT study as part of the trial management group (TMG) but with responsibility for participation and not research delivery. In both cases the adults with participation expertise and responsibility were involved in key decisions, but had the autonomy to be 'critical friends', as to some extent did young people involved in the case studies.

Y-SBNT was a time-limited research study with a team based in a number of different institutions across the country. However there was an ethos in which young people's participation was seen as a wider concept than just specific events and activities (Kirby *et al.*, 2003; Wright *et al.*, 2006). So both case studies had a 'culture' in the sense of a set of shared values that influence practice. In the case of the Y-SBNT study this centred on a shared commitment to young people's participation in the research process. Young people's participation was seen as both a process in its own right and part of other, larger systems and processes, in this case the Y-SBNT study itself as well as wider cultures of public involvement and health research. Wright *et al.* (2006) suggest that in order to be embedded a commitment to participation needs to be shared and understood by managers, practitioners and children and young people. But this study found that

commissioners, regulators and other external bodies were also an important part of the process. Cultures of participation and the factors which shaped them went far beyond the CCHP and Y-SBNT study to include the systems and structures within which they operated. In both case studies there were aspects of culture that emerged and aspects that were imposed: in the case of the CCHP from the wider NHS and voluntary sector; in the Y-SBNT study: NIHR, INVOLVE and the wider field of public involvement in health research. Some of these aspects were helpful and some less so. For example the fact that all NIHR-funded studies have to include an element of public involvement made my second case study possible, but the way in which the Y-SBNT study was managed meant that we were not able to start recruiting young advisors until the whole research team was in place and therefore had to decide on initial plans for participation without any input from young people. If we had been able to involve young people earlier we may have started off with a different approach to participation rather than ending up with one. Although there are not any existing YPAGs with relevant experience who we could have consulted I think a greater understanding of the realities of participation on the part of the principal investigator and my co-applicants, and of participation with young people affected by substance misuse on my part, might have helped to push for embedding young people's participation in the study from the outset rather than when the study was already underway (a key recommendation for any follow-up study to the Y-SBNT pilot). Procurement and recommissioning processes, along with the increasingly break-up and privatisation of NHS services, present significant barriers to embedding a culture of participation in health services. This was certainly the case in CCHP when the impact of recommissioning became increasingly evident towards the end of my work with the organisation. This also has longer-term implications for the embedding of participation, for example if key individuals leave, the CCHP ceases to exist in its current form or the new contract holders are less committed to participation.

But does a culture of participation involve young people?

Much of the literature on cultures of participation (e.g. Kirby *et al.*, 2003; Wright *et al.*, 2006) focuses on the organisational cultures within which professionals work. Although it is often said that these cultures should be shared with, and involve children and young people, I found that this was not so straightforward in practice. This study raised questions around whether a participation charter, standards or strategy necessarily need to be something to which young people formally 'sign up', as suggested by Wright *et al.* (2006) and Cutler (2003). While the aim is laudable it assumes a model of participation in which young people have ongoing involvement with an organisation, and that they are interested in being involved in the management of strategic participation. However many young

people using health services such as CAMHS, physiotherapy or school nursing would not necessarily identify themselves as a service user of the larger organisation of which the service is a part. In the Y-SBNT study many young advisors were initially much more interested in informing the development of the intervention than in reflecting on their involvement in the research process, or on young people's involvement in research more broadly. To comment on the PPI plans for example required an understanding of participation, public involvement in research and the research process, all of which were new areas for most young advisors involved. Those young advisors with ongoing involvement in the study built up this knowledge over time, but this was not possible for those young people who had one-off or intermittent involvement in the study. Informing the development of the intervention, and contributing to the design of research tools and analysis required only their expertise as former users of substance misuse services and was also what many of them were most interested in. The dispersed and diverse methods of participation in the study meant that the young advisors often had only limited contact with the whole research team, making it even more difficult to talk of a culture of participation in which they were included. However children and young people do not necessarily need to have the same or similar understandings to adults of participation and rights in order to be able to participate effectively and authentically. If a culture is rights-based and young person-centred this creates a culture of participation in which young people can be included, even if they did not articulate it as such.

12.2.3 Frameworks for participation

Leadership and responsibility

Embedding cultural change and a shared understanding of participation requires more than preaching to the converted. It needs an understanding of the systems and structures at play, particularly in healthcare organisations where management structures and lines of responsibility are often unclear and subject to competing agendas and changing priorities. A shared commitment to participation needs leadership in order to be developed and supported, including but not limited to management support for participation practitioners, maintaining participation as an organisational priority and addressing resistance to change (Wright *et al.*, 2006). This study found that, in practice, this was far from straightforward in either case study; support for participation in the Y-SBNT study from the research team was often equivocal and, although the NIHR and HTA supported young people's participation in funding the proposal and organisations such as INVOLVE, the day to day task of embedding participation in the study was left to me and my fellow public involvement lead. The CCHP by contrast had staff at all levels who were very committed to participation, and some experienced young champions (see below), but it

was also a large and complex organisation in which understanding and experience of participation varied considerably. The challenge for embedding participation in this instance is how to maintain it as a priority and provide leadership when faced with restructures and the resulting change and uncertainty.

Expertise and champions

Participation expertise, skills and champions (both formally nominated and informal) were needed to support the embedding of participation in both case studies, and this was also identified as a key issue in the critical inquiries. Champions within services can represent the views of other practitioners, cascading participation and driving implementation as well as potentially being a first point of contact for children and young people. In the case of individual participation this might mean being the person children and young people can go to if they have a concern or complaint about their experience or ideas about how things could be improved. People with in-depth understanding of participation (the 'participation professionals') in both case studies helped to ensure that it remained on the agenda, encouraged and supported the sharing of good practice and challenged and developed practice which required improvement. Participation in healthcare often relies on individual professionals and this can be a barrier to its being embedded in everyday healthcare practice, as well as creating a focus on consultation with children and young people about their individual health needs rather than collaboration in the commissioning, delivery or evaluation of health services (Blades *et al.* 2013; Ocloo and Matthews, 2016). This study found that the role participation professionals needed to play was to facilitate and enable participation rather than being seen as the people who 'do' participation, and there is a need to address tensions between the need for participation champions and expertise and the idea of participation as a collective endeavour.

Young people can be participation champions too, for example by becoming a peer mentor or producing information for other children and young people about participation or the service, organisation or project (as young people involved in the CCHP project did and Y-SBNT young advisors wanted to do in a full trial). However understandings of childhood, children's rights, citizenship and agency impact on the power and agency of children and young people in institutionalised practice (Devine, 2002). For the young people involved in the case studies motivation to become a champion for participation was often about using personal experience to benefit others, further to any personal benefits they might gain from being involved. But as young people are still rarely involved in decision-making processes in health settings and often occupy a marginalised position in healthcare encounters (Coyne, 2008) it is important to consider how much power and influence young champions can actually have in practice, so that it does not become an exercise in

'window dressing'. This involves consideration of the motivations of and benefits for young champions, and exploring with them how they can most effectively be involved in catalysing change.

Planning participation

In both case studies participation plans were an important catalyst for participatory practice: as an end goal in the CCHP and in the way in which the PPI plans synthesized and developed emerging thinking around how best to involve young people in the Y-SBNT study. In both instances the process (the CCHP workshops and Y-SBNT TMG and young advisors' meetings) was crucial to developing the understanding and practice of young people's participation, and provided opportunities for young people and practitioners to be involved in the process. It was through documenting these processes that key learning about embedding participation emerged. Given the fixed-term nature of research studies and the challenges of re-procurement of health services mentioned above, documenting both what is planned and what happens in practice is really important for the embedding of participation. Otherwise when organisations change, projects end and people leave, a lot of good work and knowledge can be lost. Drawing on existing models, tools and guidelines was found to be an important part of the planning process in both case studies, and the critical inquiry process also identified this as something that needed to happen more. The gap between the rhetoric of participation and the reality of practice identified by Berrick, Frasch and Fox (2000) could be breached, or at least narrowed, if more practice was explicitly linked to theory, models and tools and also used to refine and develop those theories and models of participation.

This study found that considering processes as well as standards of participation encouraged a more inclusive, nuanced and sustainable approach. Rather than an organisational approach in which the emphasis is on the imposition of top-down standards (e.g. Cutler, 2003) it was more helpful to talk about a process of reflective practice and collaborative learning, rooted in specific contexts, in which young people are involved from the outset. A collaborative approach in which participation is seen as a context-specific, sustainable and embedded process involving emergent learning, rather than a project, requires clear aims, outcomes and underpinning structures (Davis and Smith, 2012). This study found that any standards and outcome measures also need to be 'live' and flexible enough to adapt to the changing needs of services and young people. Many participation charters (e.g. Cutler, 2003; Wright *et al.* 2006) are based on an idea of participation in which children and young people have ongoing involvement with an organisation, and that they will be interested in being involved in the management of strategic participation. But neither of these things was the case for most of the young

people involved in the two case studies. It is unlikely to be a model that works for time-limited projects like Y-SBNT in which young people may move in and out of involvement, or for many children and young people using health services if they do not have ongoing involvement with an NHS service or identify with the wider organisation of which the service is a part. This study found that the intention to involve young people in the planning of participation was important, but how formally this was done depended very much on the young people involved, their interests and prior experience.

12.2.4 Participation in practice

Even when healthcare professionals and organisations are committed to participation, there can still be a gap between rhetoric and reality (Ocloo and Matthews, 2016). The discourses and cultures of health services and research often do not sit easily with partnership with young people (Todd, 2012). This means that children and young people's views are still not consistently sought or acknowledged within healthcare settings; they are rarely involved in decision-making process and often occupy a marginalized position in healthcare encounters (Coyne, 2008; CRAE, 2015a and b, CQC, 2015). In addition to the piecemeal approach to participation in health services there have been disparities in the characteristics of children and young people likely to participate, the types of decisions they are involved in making, and the extent to which this participation is meaningful and effective (Cockburn, 2005; Davey, 2010; Moore and Kirk, 2010; Percy-Smith, 2010). There is also uncertainty about how to increase the diversity of children and young people involved in participation in healthcare (Ocloo and Matthews, 2016) and health research (Brady, 2015). All these issues emerged in this study and we sought to address them through the creation of opportunities for shared learning in relation to both individual and strategic participation, and tools and practical support to develop both practitioners' and young people's confidence. Young people involved in both case studies spoke about the benefits of participation for their wider peer group, as well as personal benefits including being able to use difficult personal experiences to create positive change. However doing this safely required building trust and personal relationships with the adults supporting their participation, as well as being flexible and aware that some young people involved in participation may not want to be credited if that involved highlighting their use of particular services.

Although participation strategies and plans are important in developing a shared vision and building a culture of participation they are not, in themselves, enough to embed participation in practice. Participation in the CCHP needed to be embedded in routine processes such as training, supervision and team meetings, as well as being included in

documents and policies used in everyday practice. This was about more than just getting people to fill out a participation framework or contribute to a PPI plan. Internal and external dissemination were key in both building a culture and demonstrating a commitment to participation, as was drawing on the expertise of young people and voluntary sector organisations who worked with them. Critical appraisal of participation is about looking critically at the purpose, consent, method and interpretation of participation in practice (Todd, 2012). This study found that these elements need to be consistently evidenced in some form in order for participation to be shared, improved and embedded in ways that enable fundamental change in cultures and practice. But this need for evidence needs to be integrated into existing systems and processes as much as possible to avoid becoming too onerous, and also be part of a wider learning culture which involves young people alongside professionals.

As discussed in 12.2.1 embedding participation requires there to be shared understandings of what participation is and the different forms it can take (e.g. individual, strategic, collective). Understanding why participation is important involves developing an understanding of the values underpinning it: not just children's rights but addressing understandings of childhood and how this links to power, control and ideas of authentic participation. Although both case studies were trying to move towards more young person-centred participation, it was still conceptualised primarily as being about young people being *"expected to fit into institutional contexts, in an adult-driven framework"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.11), rather than shared action (Nolas, 2015; Percy-Smith and Thomas, 2010), a transfer of power (Lansdown, 2010) or a fundamental change in the relationships between organisations and young people (Davis and Smith, 2012).

But what 'say' do children and young people have about what they are participating in, and how, when and where they participate? Who decides what is done with the outputs of the participation? Who evaluates participation and decides on what the success measures are? In both case studies these decisions were still made predominantly by adults. In the CCHP much of the strategic participation activity was focused on activities like young people's involvement in recruitment and training, or supporting young people to give feedback on existing services. But it was acknowledged that children and young people still had little power or control individually or collectively over how those services were developed and delivered. There were also concerns about involving children and young people in difficult decisions e.g. when faced with funding cuts, and services being *"able to handle very empowered parents and children*".

The Y-SBNT study, as with many studies which involve young people in health research, began with an adult-led set up in which plans for participation were established before young people became involved, rather than starting with the young people we wanted to involve and collaboratively exploring what would work best for them. If the primary purpose of young people's participation in research is for them to comment on draft research materials and other documents developed by adult researchers, who then go away and decide which of this feedback they will use or not use, this is nearer to consultation than authentic participation (Cockburn, 2005) or co-production and emancipatory models of public involvement (Beresford, 2013; Gibson, Britten and Lynch, 2012). That is not to say that this is not an important role for young people to play but the dominance of the advisory group (YPAG) model means that young people's participation in health research tends to be centred around meetings in adult institutions, in which researchers show information sheets and other documents to young people and get their feedback on how to make these more 'young people-friendly'. While this does have value it could potentially be an easy way for researchers to 'tick the public involvement box' without reflecting on whether there are other, more collaborative and authentic ways in which they could involve young people in their work. It also raises issues of diversity and inclusion, as in my experience the established YPAGs tend to be generic and populated by academically-able and research-aware young people. This certainly has some advantages, for the reasons we sought to involve participation-aware young people in the CCHP workshops: we could more easily get to a shared understanding between adults and young people about research or participation. But such an approach can also exclude those young people who are less frequently heard.

There are now a number of health research YPAGs for young people with specific conditions or experiences, or attached to particular projects who can offer specific experiential expertise that the generic YPAGs are unable to do (e.g. NIHR CRN Mental Health, 2016). But my research has highlighted a number of important gaps which need to be addressed: the need to map systematically when and how children and young people are involved in research, and who is or is not involved; and to assess the impact of young people's involvement on health research for the young people involved and their wider peer group, for researchers and research studies and for research bodies. For example the NIHR Clinical Research Network: Children currently records which of its adopted studies have public involvement, but does not distinguish between the involvement of parents and carers and children and young people, much less record any demographic or other characteristics of children and young people involved in research studies. The voices of young people who are less frequently heard are also often absent from the literature on

young people's participation in research (Richards, Clark and Boggis, 2015). Much of the limited but growing literature on young people's involvement in health research focuses on the benefits, impact and outcomes of that involvement (e.g. Boeck and Fleming, 2012; Moules, 2005) and there is a general lack of critical reflection on young people's participation in health research (Bird, Culley and Lakhanpaul, 2013; Wilson *et al.* 2015). This study addressed through reflecting on young people's involvement and the role I and my co-applicants played in embedding this in the Y-SBNT study, through my doctoral research. Another issue which emerged in Y-SBNT, and to a lesser extent CCHP, was whether some children and young people were less frequently heard because they were perhaps not interested in participation, or opting out by remaining silent or not responding to contact (Waldman, 2005). This is an area which would be difficult but interesting to research further: whether and when children and young people choose to be involved, or to opt-out of participation and how they choose to do so.

Participation does not operate, and cannot be embedded, in a vacuum. The legislative, policy and practice context discussed in Chapter 3 provides some key drivers for both case studies. Both case studies and the critical inquiry process discussed in Chapter 5 identified the need for more sharing of innovative practice with the wider sector(s) and not just within the organisation or project. But there is a question of how open health services and researchers are to genuinely collaborative and young people-led initiatives that overturn established convention given the cultural issues outlined above.

Who is and who is not involved

There is a lot of rhetoric in health services and research about inclusive practice and diversity, but in practice it appears that participation and a 'child first' focus on children's rights can unintentionally marginalise those who are less frequently heard (Curran and Runswick-Cole, 2014, Ocloo and Matthews, 2016). In both my case studies it was the more articulate, confident and engaged young people who were involved. In both we tried to address this: the CCHP were actively seeking to address issues of inclusion and diversity in both participation and use of services, and identified that the two were linked so improving one would potentially improve the other. In the Y-SBNT study we continually reviewed and revised our plans to involve young people in response to feedback from young people and the organisations through which we were attempting to recruit them. However in both cases we only partially succeeded and there was still a lot more that needed to be done to make participation more inclusive. With the CCHP I had hoped go out and talk to children and young people who were using, or could potentially use, CCHP services but didn't have prior experience of participation to find out their views on the strategy, young people's film and other outputs. There were a number of reasons this was

not possible, not least the fact that the main forum in which learning was taking place was the collaborative workshops. On a practical level these took up a lot of time, generated huge volumes of material and were quite difficult to keep manageable and within the confines of a PhD study, leaving very little time for anything else. If I had stepped back from the process at some point to explore emerging learning with other, less participation-experienced, children and young people this could have added some very different perspectives to those of the young people involved. But then the young people involved in the workshops had a wide range of perspectives and experiences, and exploring the views and ideas of young people who are not yet involved in participation would have perhaps been a different project. In CCHP we started with the professionals and young people who were engaged with participation, with the idea that the resulting strategy would then be rolled out across the organisation. But, as with young people, it would have been interesting to go out to services or other meetings and talk about the things coming out of the strategy workshops. The people I was working with were interested in participation and saw the value of what we were doing but embedding participation across an organisation means developing something that everyone can buy into, and the time limitations of a PhD meant that I had to step out before we got to that point in the process.

With the Y-SBNT study it would have been useful to know more about the services that did not respond to requests to disseminate information on the opportunity for participation to the young people with whom they were in contact. We also had ten young people who only engaged with the study once, all of whom signed consent forms and said they would like ongoing involvement but then stopped responding to our attempts to contact them. Waldman (2005) argues that young people with complex needs, especially if they are living in care or in crisis, may feel powerless about decisions affecting their life and find it difficult to actively say 'no' to participation, instead opting out by remaining silent or not responding to contact. This was certainly our experience in the Y-SBNT study as, despite various attempts to get feedback from young people involved early on in the project, all the young people who opted out of further involvement did so by not responding to contact rather than actively opting out. This means that I can only hypothesise about why other young people given information on the project did not choose to get, or stay, involved.

Both case studies highlighted the need for flexibility and working in young person-centred ways, and it was important to think carefully and who was and was not able to be involved. However the study also found that not all young people wanted to or were able to be involved. So inclusive participation involves seeking to provide opportunities for any

young people who want to be involved to do so in ways that work for them, but acknowledging that if, when and how they are able to be involved is ultimately a matter of individual choice. Young people have a right to be involved in matters that affect them, but they also have a right not to be involved.

The role of parents, carers and support services

In both case studies young people's participation was about more than young people. The participation of children and young people often includes adults, either parents and carers or professionals, who may as act as 'gatekeepers' and both enable and potentially constrain children and young people's participation (Cree, Kay, and Tisdall, 2002; Hood, *et al.*, 1996). Healthcare professionals and parents play a significant role in whether and how children and young people's efforts to participate are facilitated and supported in clinical settings, and many have reservations or concerns about children and young people's active involvement (Coyne, 2008). This study found that for some young people using health services or involved in research support from parents or carers may be a key factor in making participation possible. But for others it may silence or override their participation, particularly given that the dominant model in health services is still one in which the *"consultation takes place between a health professional and the parent as a proxy for the child"* (Redsell and Hastings, 2010, p.xiii). It is important not to conflate young people's and parents' participation but to see parents and carers as a related but separate group to children and young people; their views should also be heard as service users but alongside rather than as a proxy for young people's participation. It is also important not to conflate parent and carers' participation as service users or members of the public in their own right with their role as gatekeepers to and supporters of children and young people's participation.

The role of the voluntary sector was central to the successful involvement of young people in the study: in the CCHP because of the participation expertise and support provided by Barnardo's, and in the Y-SBNT study through substance misuse services recruiting and providing support to young advisors. The latter was key to the embedding of young people's participation in the study, as many young advisors were estranged from their families or living independently for another reason. Getting and keeping young people involved in the study really benefited from engaging them via services and staff with whom they had established relationships. The services that did support young people's involvement in the study generally did so because a worker had 'got' the study and was enthusiastic about the opportunity for participation for the young people with whom they worked. But the substance misuse sector does not have an established tradition of participation and at times we faced at times an uphill battle in convincing services to pass

information onto young people or support their participation. So as with parents and carers in the CCHP for some young people involved in the Y-SBNT study support services were a key factor in making participation possible, but for others it may have silenced or overridden their opportunity to participate.

12.3 Are children's rights an essential pre-condition for embedding participation in health services and research?

This study was located within a children's rights-based theoretical framework (see 2.5), which enabled me to open up to critical inquiry existing assumptions and practices concerning young people's participation and how this relates to children's rights. I found that children's rights are not an explicitly essential pre-condition for participation, in that it is possible for people to pay lip service to the CRC without embedding participation in a meaningful way (for example when that participation appears to be tokenistic or 'window dressing' or the CRC is merely mentioned in passing). Echoing Hammersley (2015) I found that children's rights tended to be accepted at face value with little critical reflection. A rights-based approach to participation in health services and research means considering all relevant rights, not just article 12. As similarly argued by Alderson (2014) and Tisdall, (2015) the challenge is in understanding how the tensions inherent in the CRC between participation or autonomy rights and welfare or protection rights impacts on whether, when and how young people are involved in decisions about their own care, health service development and research.

The evidence from my study supports Lansdown, Lundy and Goldhagen's (2016) point that the CRC provides a framework which can underpin rights-based approaches to clinical practice, policy design and health research. Therefore I think that children's rights and the CRC are an implicitly essential pre-condition for embedding participation in ways that are meaningful, effective and sustainable, as discussed in 2.3.2 with reference to the UN General Comment on Article 24. It is less important whether practioners can cite the CRC or relevant articles, or if children and young people using services or involved in research are aware of the CRC and their rights. What this study found is that what matters is whether and how people, organisations and institutions conceptualise children and young people as active citizens with a right to have a say in matters which affected them, and have a genuine commitment to inclusive and collaborative practice which seeks to work in partnership with young people in ways that work for them. This relates to both how professionals enable young people to have a say in their own care (individual-level participation), and in how strategic participation is planned for, practised and reviewed: with children's rights at Article 12 at the centre of any conceptualisation of participation

(Lundy, 2007; Seymour, 2012). This is where this study found that the role of people with participation skills and expertise was key: in ensuring that understandings and cultures of participation have a grounding in children's rights. Children and young people may not be able to fully understand their rights until they have experienced meaningful participation, but this study found that they generally know whether the participation they have experienced is tokenistic or authentic. A rights-based approach to practice is therefore less about telling children and young people that they have rights, although this is still important, than about seeking to provide meaningful opportunities for participation in which rights are embodied in the ways in which people practice. Despite increasing commitment to children and young people's participation healthcare decisions are still often imposed by professionals rather than made by or with children and young people (Percy-Smith, 2007). Furthermore this study found that taking a rights-based approach to health services has the potential to change how health professionals view and treat children and young people through changing their cultural view of children and childhood (Webb *et* al, 2009).

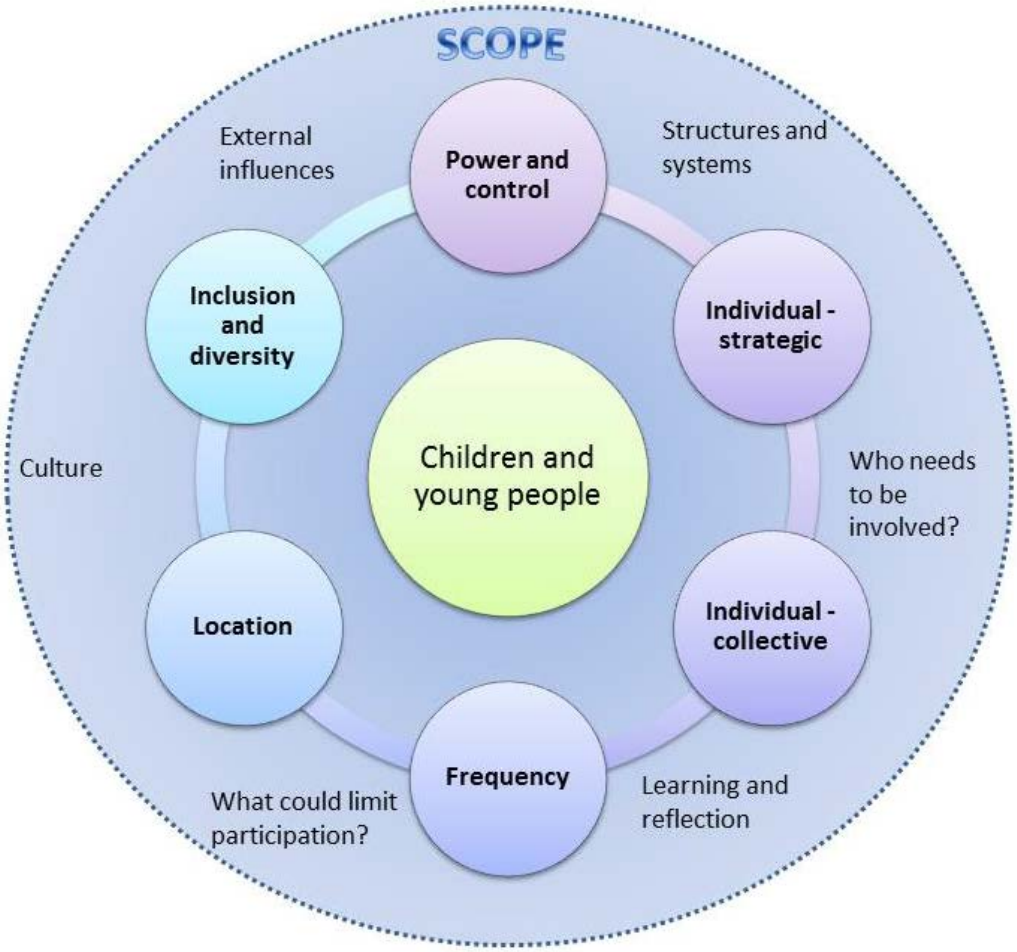
The lack of critical reflection on children's rights in the literature on children and young people's participation in health research is also an important omission to consider. Although many publications mention the CRC in their rationale for involving young people in the research process, this tends not to go beyond referencing article 12 and children's 'right to have a say in matters that affect them'. This relates to the need to do more in both health services and research to problematise the notion of participation being mainly about children and young people being provided with opportunities by adults and *"expected to fit into institutional contexts, in an adult-driven framework"* (Groundwater-Smith, Dockett and Bottrell, 2015, p.11). This study found that taking a rights-based approach is a key way to address this, and therefore children and young people, and their rights, are at the centre of the framework discussed in 12.4 below.

12.4 A rights-based framework for embedding young people's participation in practice

Figure 11 below is a synthesis of the key elements which emerged from this study, with reference to the case studies but also drawing on the critical inquiry process which preceded them and underpinned by the theoretical framework in 2.5. To be embedded there needed to be an understanding of all these different elements in relation to where young people's participation currently sits and where people would like it to be. This may not be about identifying exactly where an organisation, project or service or even individual is in relation to this framework, as this may not be helpful or even possible. It might instead be about collaborative reflection on the various dimensions and how they apply in that particular context. Some blurring between these different dimensions is also helpful in reviewing and adapting pre-existing understandings of participation in relation to the realities of participative practice.

In June 2016 I was invited to co-facilitate a workshop on developing children's participation for Wellchild, a UK charity who support children and young people living with long-term or complex health conditions. I used the framework below in the workshop as a tool to support participants to consider how best to involve children and young people in the organisation's work, by considering where they currently were in relation to each of the dimensions, and where they would like to be in the future. The feedback from the workshop was positive with only a couple of minor changes, which have been incorporated into the framework: considering where and how to best get input from children and young people when developing ideas for participation and working with existing groups or forums as well as setting up new ones.

Figure 11: A framework for embedding young people's participation



Young people are at the centre of the model because of the centrality of children's rights to this study, as well as the importance of developing authentic participation in young person-centred ways and in collaboration with young people and in ways that work for them. The key point here is that the focus of embedding participation is on the young people who are, or could potentially be involved. But at the same time their participation is bounded by 'scope', the services and systems in which that participation takes place.

Scope highlights the importance of defining the boundaries within which young people's participation will be embedded. As with my case studies this may include one or more services, projects or organisations as well as young people, services, a wider organisation, regulatory bodies, NHS, NIHR and other commissioning and regulatory bodies. It may also include families, carers and support services. It involves considering what is understood by, and required from, participation and the organisational culture in which it will be embedded, as well as available resources and the limits of young people's possible influence. In the Wellchild workshop the first exercise was getting participants to think about the scope within which they would be working, including the internal and external influences which could support and limit young people's participation in the organisation.

The focus here is on ensuring that participation is ambitious but also realistic and sustainable.

Within the scope there are a series of interconnected dimensions, set out in Table 4 below, all of which play a part in determining both what young people will participate in and how they will participate:

Table 4: Framework dimensions

Dimension	**Key questions to consider**
Individual-strategic	What level and types of participation are young people involved in?
Individual-collective	How are young people participating? Individually, in a group or both?
Frequency	Is participation activity a one-off, does it happen at key points/intermittently or is it ongoing?
Location	Does participation takes place in fixed or varied-locations? Does activity take place online or in a physical location? Do young people come into adult settings or do adults go to young people? Within this also consider whether participation involves going to pre-existing groups or other forums or establishing new ones, or a combination of both.
Inclusion and diversity	Who needs to be included for the participation to be meaningful and relevant to the service, organisation or project? Who is and is not currently or potentially included in participation? What would enable them to be included?
Power and control	What say do young people have in what they are participating in, and how, when and where they participate? At what stage in the development of participation plans will young people be involved? Who decides what is done with the outputs of the participation? Who evaluates participation and decides on what the success measures are?

This is not intended to be a model which outlines how participation should happen and there are no right or wrong answers. But this study found that for participation to be embedded people need to be aware of where they are, and where they would like to be, in relation to all these dimensions. It is something which needs to be revisited as practice develops and changes. The focus of this framework is on having an understanding of what is happening in reality, not about vague statements and aspirations.

A second stage, which emerged during the Wellchild workshop, was to identify the systems and structures needed to implement the ideas identified through working with the framework in relation to staffing, expertise and champions; evaluation, evidence and

impact; reward and recognition for young people involved; training for young people and adults and what funding and other resources would be needed.

Gibson, Britten and Lynch (2012) argue for an emancipatory framework for public involvement (participation) in health and social care *"which incorporates cultural, political and social dimensions of a diverse and unequal sector and society"* in order to empower, capacitate and support people to *"hold the NHS to account"* (p.535). Although this is a framework, it does not presume to address all of these issues; but it nonetheless draws on both the theoretical frameworks underpinning this study, the experience of adults and young people involved in the critical inquires and the extensive in-depth work with the two case studies. It seeks to address criticisms of other models as not having a sufficient theoretical basis (Malone and Hartung, 2010), emphasis on impact (Tisdall *et al.* 2014) or challenging adult-child power relations (Davis and Hill, 2006; Percy-Smith, 2016). One of my suggestions for further research is to test and develop this framework, in collaboration with children and young people, in other health services and research studies and more widely.

12.5 Study limitations

Action or participatory research?

This study was located within a participatory paradigm (Heron and Reason, 1997) using an action research approach to focus on a social or political agenda for reform, in this case a rights-based, participatory approach to embedding young people's participation in health services and research. But although action research approaches were central to this study the way in which my case studies progressed meant that one followed the model of self-reflective cycles (Kemmis and McTaggart, 2000) much more closely that the other. The CCHP case study followed an action research methodology more closely, as it consisted of working towards practical outcomes (the development and implementation of the participation strategy and framework) as well as creating new forms of understanding (Reason and Bradbury, 2008).

When I planned the Y-SBNT study I intended to use action research approaches to work with the young advisors. So as well as involving them in the research process I wanted to engage them in cycles of reflection on the process of involvement. The idea was to create a relatively clear distinction between this PhD study (reflecting on the participation process) and my role in the Y-SBNT study team (facilitating that participation process). I had also hoped to have one or more workshops or similar events in which young advisors and the study team would come together and reflect on learning about young people's

involvement in the study. The intention was that we could then collaboratively refine how young people were involved in the study, and also that most of the learning pertaining to this study would emerge from meetings with the young advisors:

> *"The collaborative process is likely to involve my facilitating participatory inquiry with stakeholders in each case study informally in the context of practice, as well as dedicated inquiry workshops which will provide key opportunities for reflection on the dynamics of participation and learning in practice… [the Y-SBNT study as a PhD] case study will involve exploring and reflecting on young people's participation through co-inquiry with the young advisors and adult researchers. This is likely to include consideration of impact and outcomes of involvement (including how the research tools are adapted and developed as a result of children's input) as well as considering issues of power and organisational cultures, and the relationships between professionals and the young people involved".*
> (Application to UWE Faculty Research Ethics Committee, 2013, pp.3-4).

The absence of a core group of young advisors involved in regular face to face meetings meant that the initial idea of collaborative workshops bringing together young advisors and the study team was not possible. And while there was a process of co-inquiry with both young people and members of the TMG and TSC for practical reasons this tended to happen 'informally in the context of practice' rather than as 'dedicated inquiry workshops'. So for example young people explored and reflected on their experience of participation in young advisors' meetings and in the development of the study report chapter on public involvement. Participation was on the agenda at every TMG and TSC meeting with one focus group for each group at the end of the process, at which I sought to consolidate learning. However, as discussed in 4.1:

> "*…no one may mandate in advance that a particular research process will become a fully developed participatory action research project. Participation is a process that must be generated. It begins with participatory intent and continues…within the limits set by the participants and the conditions*". (Greenwood, Whyte and Harkavy, 1993, p.175-176)

This case study certainly had 'participatory intent' and was underpinned, as outlined in 2.5, by a framework of participatory, rights-based research through which I sought to engage in practical and collaborative inquiry with both case studies. Taking a flexible approach enabled me to facilitate a process of investigation in ways which had meaning for those involved (McNiff, 2013). But I was at times perhaps focused too much on 'non-epistemic' quality criteria of 'giving voice to the marginalised' and 'bringing about practical effects' (Hammersley, 2007), as well as making sure the research was relevant to participants and responsive to the context in each case study (Hughes, 2008). In retrospect I would have liked to have reflected on the impact of an iterative and context-specific approach to knowledge creation on the research process as the study unfolded.

Case studies

Taking a case study approach was a very useful methodological approach with which to investigate the embedding of young people's participation in health services and research. It enabled to me to construct the case studies as the sites for encounters and social action related to young people's participation from multiple perspectives, exploring the meanings brought by different actors, and using multiple methods and data to explore and interrogate instances in action (Chadderton and Torrance, 2011; Ritchie *et al.* 2014). Furthermore, using a participatory, action research-informed approach located this study within a research tradition which focuses on improving decision-making and practice, and emphasises *"planned development in situ"* (Chadderton and Torrance, 2011, p.53). Both case studies provided unique opportunities to explore what it means to embed participation, and gave me a chance to look across two areas (health services and research) which often exist in parallel.

However the two case studies were very different in terms of context, setting and approach. I could have done a very interesting PhD on one or other case study alone, and in doing so would have had more time for reflection during the research process, and to analyse the material and learning which emerged. As discussed in 4.8 the variety and volume of data presented challenges for analysis which would have been less of an issue with one case study. However I think that the most interesting material emerged in relation to the points of commonality and difference between the case studies. They were both ultimately focused on young people's participation leading to an improvement in health services: one through supporting children and young people's participation as individual services users and in strategy and planning, and the other supporting their participation in a research study to ensure that the resulting intervention was relevant to young people who might receive it in the future. The intersection between participation in health services and health research is an area of growing interest in both research and practice but there have been as yet been no published studies which look at this in relation to young people's participation. As discussed above the case studies were very different both in context and how the work I did with them panned out, as well as my own experience within them as insider or outsider researcher.

My role in the process

In seeking to understand what it means to embed participation, I did so in two settings in which I became to some extent also embedded. The nature of these two case studies therefore influenced both the approach I chose to take and how the research process

evolved, but in both I was an active contributor to the process rather than a neutral observer. With the CCHP I came in as an external facilitator but, for the duration of the time I was working with them, was embedded in the process of developing the participation strategy and framework. In the Y-SBNT study I was a co-applicant and member of the TMG as well as having responsibility for young people's involvement in the study, so the success or otherwise of young people's participation in the study was ultimately my responsibility and something I was being paid to do. I therefore had a strong vested interest in young people's participation being successfully embedded in the study and to rationalise my responses to some of the challenges I faced in attempting to do this. This is not a study in which I sought to have an uncritical positivist objectivity; neutrality and objectivity are generally not seen as necessary, or even desirable, in action research (Stringer, 1999). I also think that my 'insider' position gave me unique insights that I would not otherwise have gained, and benefited the Y-SBNT study through a more reflective participation process than would have happened if I was just leading young people's involvement in the study. The learning that I sought to capture for this PhD study also informed the development of a model of participation for a potential follow-up study and the chapter on young people's involvement in the Y-SBNT report for the HTA. But in retrospect I think I underestimated how difficult it would be to manage this dual role, particularly when we started to face challenges with involving young people in the study.

Using a participatory research approach enabled me to generate knowledge from my experience of working with the case studies, *"a living process"* of collaborative learning in which I was an actor (McNiff, 2013, pp.28-29). But balancing working collaboratively towards practical outcomes (Reason and Bradbury, 2008) with the requirements of academic study, and particularly doctoral research (Herr and Anderson, 2015) was not straightforward. Looking back on my work with the CCHP I was perhaps too focused on the action phase of the action research cycle, and in retrospect could have been led less by the group's desired outcomes (development and implementation of the strategy and framework), and reflected more on the best way to get there and the learning emerging from this process. This was perhaps partly to do with my being new to action research as opposed to participative workshops, but also because this research topic is so close to my heart and such a core part of my professional identity so the desired outcomes were also very important to me. Although I have positioned myself as an outsider researcher in the sense that I was not a CCHP employee, I ended up being partly an insider in that I did not just come in and neutrally facilitate a process of reflection and learning but brought my own experience, ideas and values. As with the Y-SBNT study if I were to do this study again

I would step back more often in order to gain some critical distance and reflect on the process and my role within it.

Ultimately the learning which emerged was richer for my having played the roles that I did. But if I were to do this study again I would make a point of stepping back and reflecting on the process and my role within it more often, as the way in which participation changed in unexpected ways throughout the study had unanticipated consequences for this study which I did not always appreciate at the time.

12.6 Implications for future research

There are several potential follow-up studies which could be developed from this work: firstly, looking at the impact of restructuring and NHS changes on the work undertaken at CCHP and the impact of these changes for the implementation of the strategy and the embedding of participation more general. Secondly, if the Y-SBNT pilot is followed up by a full trial which implements the model which emerged from this study, a follow-up study which explores the learning from this would be very useful. Thirdly, to further test and develop the framework presented in 12.4 in other health services and research studies and possibly more widely.

This study identified the need for further research on who does and does not get involved in participation, and how different models and methods of participation enable and create barriers to more diverse participation in health services and health research. This could explore the motivations of young people who do get involved and find out why they did so and what kept them engaged; as well as exploring whether and why young people may choose not to be involved, or to opt-out of participation, and how they choose to do so.

While there is increasing interest in getting children and young people's feedback on health services, data are not routinely collected or collated on how they feel they have been listened to or involved in decisions about their healthcare. Related to this research on the role of parents, carers and support services in enabling, facilitating and presenting barriers to children and young people's participation at both individual and strategic levels would be helpful.

Given the lack of critical reflection and empirical evidence on children young people's participation in health research and the dominance of the YPAG model, further research is needed to systematically map when and how young people are involved in health research. This could take the form of comparative evaluation of who is or is not involved, methods of involvement, and the impact of young people's involvement on health research for the

children and young people involved and their wider peer group, for researchers and research studies and for research bodies. Similarly there would be considerable benefit to a study which mapped and evaluated different approaches to involving young people in health services at national and local levels. Related to this and the issues of power and control discussed in this thesis, there is considerable scope for research on developing and learning from more authentic models of children and young people's participation in health services and research, for example considering shared action, co-production and young people-led initiatives.

12.7 Conclusions

This study sought to understand how organisational culture, systems and practice support or create barriers to embedding young people's participation in particular two case studies. As outlined in 1.3 I have long been interested in research as a tool for social change, and sought through this PhD to make a contribution with relevance to policy and practice as well as a contribution to academic knowledge. My research approach was therefore underpinned by a participatory, rights-based framework, through which I engaged in practical and collaborative inquiry with the two case studies with the aim of 'giving voice to the marginalised' and 'bringing about practical effects' (Hammersley, 2007). In addition to the context-specific learning which emerged from this process the study also makes a wider contribution to knowledge through highlighting processes and dynamics that are relevant in other contexts in health services, health research and potentially more widely. The study found that embedding participation requires an understanding of how people conceptualise participation and children's rights how these understandings inform culture and practice, as well as how the cultures and ways of working in health services and research inform how participation is understood. The study echoed the existing literature in concluding that embedded participation needs to be part of the everyday processes, but adds to this with the finding that 'embedded' does not necessarily mean completely integrated, as it is easier to develop participation in young person-centred ways if participation is a quasi-autonomous process with specialist input and expertise. The study found that participation needs to be embedded in everyday practices, systems and cultures, but at the same time young people and those facilitating their participation, need to be able to be 'critical friends' and to have the independence and resources to be able to drive a more ambitious vision of participatory, inclusive and socially-just participation (Todd, 2012). Without this participation can too easily revert to being a top-down, 'tick box' exercise which does not stimulate meaningful change in practice and in the relationships between young people and professionals.

This study further highlighted the need to focus more on the individual-collective as well as individual-strategic dimensions of participation. Considering how young people are involved, and who is involved, as well as what they are involved in has implications for who is included and excluded from participation opportunities, and for adult-child power relations. Participation in health services and research is still primarily adult-initiated, context-specific collective participation in formal settings rather than shared action or a transfer of power. This study sought to address this by developing a framework which addresses the gaps in the literature on how participation can be embedded in professional practice and young people's experience of participation. The framework provides a means to consider how participation in health services and research could be driven by discourses on children's rights and participatory practice as well as agendas of public involvement, engagement, 'patient experience' and 'voice'.

As well as the potential to further develop practice this study identified the need to capture learning which may be lost. The current climate of austerity and increasing privatisation has implications for children and young people's participation in health services and research, and in both areas learning from participation is still not routinely captured or shared which can mean that good and innovative practice is lost. So this thesis, while focused on what embedding participation could look like in the future, is also a document of two examples of participation which at the time of writing had ceased to exist in the form in which I worked with them. Embedding participation therefore requires critical reflection and shared learning as well as an understanding of the wider systems and structures which can facilitate or present barriers to participative practice. In this challenging climate it is more important than ever that young people's participation is effectively embedded in practice and that the rhetoric of participation becomes a reality.

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Appendix 1: Literature review protocol

Main focus: to critically explore the relevant literature in order to develop a theoretically-informed rationale for this research (Braun & Clarke, 2013).

Process:

- Inclusion criteria were drawn up to identify parameters on the literature to be included;
- Search terms and key words were defined and documented;
- A range of sources, datasets and libraries to be searched were identified through my own searching and suggestions from UWE library staff, my supervisors, colleagues and expert advice from others in the field;
- Ongoing handsearching of relevant journals;
- Further hand searches of reference lists in relevant journal articles and reports, alongside the identification of other relevant material via study groups, academic colleagues and online networks, particularly Twitter;
- Given the participative nature of this research, participants in both the critical inquiries and case studies also contributed to the identification of material included in this review;
- Relevant material, once identified, was synthesized, summarised and used to identify key themes and debates and provide a theoretical framework for this study;
- Key themes and debates underpinned my work with the two case studies and my identification of initial themes for my analysis;
- Emerging learning from the research process then informed further searching of the literature during the final writing of this thesis.

Searches for available literature for inclusion in the review were mainly conducted via UWE and the British Library and included the following electronic databases:

- AMED (Allied and Complementary Medicine)
- ASSIA (Applied Social Sciences Index and Abstracts)
- BioMed
- Cochrane Library
- Community Care Inform
- DOAJ (Directory of Open Access Journals)
- EthOS
- HMIC (Health Management Information Consortium)
- IBSS (International Bibliograpy of the Social Sciences)
- Index to Theses
- invoNET
- MEDLINE
- NICE Evidence Search (formerly NHS Evidence)
- PubMed
- ScienceDirect
- Social Care Online

- Social Policy and Practice
- Zetoc

Set up alerts and handsearching of key journals including:

- Children and Society
- Children's Health Care
- Health Expectations
- International Journal of Children's Rights
- Journal of Paediatrics and Child Health
- Research Involvement and Engagement

I also searched for **grey literature** (mainly but not limited to legislation, government guidance, reports and online resources; and public and voluntary and community sector guidance, reports, tools and toolkits, and online resources) via some of the databases above and databases and websites including:

- Department of Health, www.gov.uk, www.legislation.gov.uk,
- NHS England, National Institute for Health and Care Excellence (NICE)
- Participation Works, Children's Rights Alliance for England, Office of the Children's Commissioner
- Various voluntary and community sector organisations including Barnardos, National Children's Bureau, National Youth Agency, NSPCC, Save the Children
- UNICEF, UN Committee on the Rights of the Child
- INVOLVE (and invoNET as above)
- Patient Voices, Healthwatch

Search terms/keywords included:

- Child/ren; young people/person; youth; young; early years
- Participation; involvement; engagement; voice/s; listen/ing; hear/d/ing; citizen/ship
- Children's rights; rights; UNCRC
- Health/ health services; NHS; wellbeing; community health; hospital/s; GPs, child health/paediatric(s)
- Patient and public involvement/public involvement/PPI; participative research; peer research/ers; young/youth researchers
- Childhood; sociology of childhood; child/hood research

As the focus of research was the participation of children and young people in English health services and research, the principal geographical focus of the review was the UK but, where international evidence was pertinent/appropriate, this was also included.

Date range: 2000-2016 or earlier if identified as relevant key text

Age range: 'children' are generally defined in law and policy as aged 0-18, but some studies, services and projects working with young people can include those aged up to 25 or even older. Therefore no formal upper limit was set as long as the document clearly related to the participation of children and young people.

Youth Social Behaviour and Network Therapy Study - Information for Young People

What is the 'Youth Social Behaviour and Network Therapy Study'?
The study is a three-year project which has two main parts. In the first researchers are looking at how to adapt an intervention (way of helping people in services) called Social Behaviour and Network Therapy (SBNT) that they have developed for adults using drug and alcohol services, so that it can be used with young people (up to 18) and their families. In the second part of the study the researchers will test out this intervention by delivering it to some patients in services and seeing how well it works.

The project team (see attached document) are looking for young people aged up to 21, who have experience of using drug and alcohol services between the ages of 12 and 18 and are interested in working with us on the project.

What is research?
Research can mean lots of different things, but generally it means a process of finding things out by collecting information (data) in order to answer questions and provide reliable new knowledge. For this project we would be researching how to adapt the SBNT intervention so that it is relevant and useful for young people and their families.

What is evaluation?

Evaluation uses many of the same methods as research, but is about assessing something like a project or programme to find out what has worked well or could have been better. As well as evaluating how well the intervention we develop in the first part of the study works (see above) Louca-Mai, who is working with xxxx to support young people's involvement in the study, is also doing a project on children and young people's involvement. As part of this she will be talking to young people and adults involved in the study about how young people's involvement can best help to make the study, and therefore services for children and young people, better.

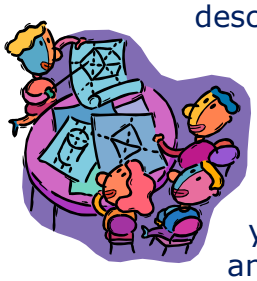
Who are the researchers doing the project?
Along with this information sheet, you should also have been given a document with information about the project team. This tells you who you'll be working with and what they'll be doing in the project.

Who can be involved?

We are looking for up to 12 young people aged up to 21, who have experience of using drug and alcohol services between the ages of 12 and 18 but are no longer in treatment, and can come to meetings in London. You have been given this information sheet because an adult you've been working with thinks it might be something you might be interested in. You don't need to have previous experience of research or advising but you should be interested in getting involved and learning some research skills. If more than 12 young people want to be involved we will select a group with a range of ages and experience.

What would I have to do?

This is a really important role and a chance to make sure that this study looks at the things you think matter to young people who use drug and alcohol services, as well as to help Louca-Mai look at how involvement in projects like this can make services for young people better. The role description you should also have been given gives you some ideas about what would be involved and what you can expect from us, but we can also change this document if we agree as a group that new things need to be added as the project goes on.



The group will meet in London during school holidays, evenings or weekends. There will probably be about 12 meetings over the three years of the project, with 6-8 in the first year and then 2-3 in the second and third year. We can also contact you in between meetings by email, text or social media like Twitter and Facebook (if you want us to), and you can get more involved in the project that way if there are things happening in between meetings that you're interested in.

One or two young advisors may also go to meetings of the whole project team, so that young people's views get heard at these meetings too. This may be the same young people each time or it may change, depending on what we all decide when the project starts.

If I get involved, what will you do with the information I give you?

Only people working with you in the project team will have access to your personal information (name, address etc). When we record or write up our discussions these will be anonymous – so when we write things about young people's involvement in the project we will not use people's names (unless you want us to, for example to be credited as a young advisor). Recordings and personal information such as your application form will be kept in a secure filing cabinet by Louca-Mai, or a password-protected computer.

What will happen if I don't want to carry on with the project?

You can stop being part of the project at any time by contacting Louca-Mai or Lorna and letting them know.

How do I take part in this project?

If you are happy to take part in the project, please complete the enclosed consent form and return it to Louca-Mai or the person who gave you this information. When Louca-Mai receives the consent form she will contact you to talk about what happens next.

Who is organising and funding the study?

The National Institute of Health Research (NIHR) funds the project as part of the Health Technology Assessment (HTA) programme of research. The project is based at Birmingham and Solihull Mental Health Foundation Trust and the research team are based in Birmingham, York, Bristol and London.

Contact for further information?

If you have any questions about the project, please speak to the person who gave you this information or contact Louca-Mai at:

xxx

Children and Young People's CCHP Participation Project - Information for Young People

Hello, my name is Louca-Mai Brady. I'm doing a project at the University of the West of England on how children and young people are involved in health and social care services, and I'm looking for young people to work with me. I'm passionate about children and young people having a say in the services they use, and being involved in projects to help make this happen. I have done lots of research with children and young people, including training and supporting young researchers in my last job at the National Children's Bureau. I live in London with my husband, baby twins and a cat but come down to Bristol often as this is where I am doing my research. I am also a trained yoga teacher, but don't get much time to teach yoga at the moment!

What is the project?

I am doing a project at the University of the West of England on how children and young people are involved in health and social care services. As part of my project I will be working with North Bristol NHS Trust (NBT) and Barnardo's HYPE project from September 2013 until summer 2014 to find out about children and young people's involvement in the Community Children's Health Partnership (CCHP) through things like staff recruitment, training and other ways in which young people help make CCHP services better. The aim of the project is to find out what is needed for this involvement to work well for young people and adults, and how it can make services better.

What are 'health and social care services'?

Health and social care means services provided by the National Health Service (including GPs, clinics and hospitals), local authorities (for example when children are in foster care or children's homes) and public health (giving people information to prevent disease and promote good health). The CCHP provide health and social care services.

Who can be involved?

You have been given this information sheet because an adult you've been working with thinks it might be something you would be interested in. I would like to work with children and young people aged 12-18 who have been involved in the CCHP and HYPE and are interested in helping to develop and improve ways of involving young people. You don't need to have previous experience of research or advising but you should be interested in getting involved and learning some research skills.

What would I have to do?

Being involved in the project will involve coming to meetings and groups with other young people and/or adults to talk about your experience of and ideas about being involved in the CCHP and how we should do things in the

project. We will also look at the information I collect and talk about what it means and what we think should happen next.
We may decide to do other things as the project goes on, depending on how adults and young people involved in the project want to do things.

If we decide that it would be good to talk to other young people who have used CCHP services some of the young people involved in the project may want to help me with this by doing things like interviews or focus groups. If you want to do this you will get training and support to help you.
We will also agree a role description which will explain what you will do in the project and what you can expect from me, HYPE and the CCHP.

How much time will it take?
That depends on how much time you have and how much you want to be involved! You could be involved in this project in different ways, for example just coming to a few meetings, or being more involved at different stages depending on when you're available and what you're interested in.

Are other young people involved in the project?
Yes. The project is happening in two areas (case studies). One is the CCHP and the other is a project working with young researchers who have used drug and alcohol services. I am also working with other groups of young people about the project and getting their ideas about young people's participation in health and social care services. One of these young people's groups gave me advice on what information I should put in this document.

What will you do with the information I give you?
Only Louca-Mai will have access to your personal data (name, address etc). When I record or write up interviews or other discussions these will be anonymous – so when I write things about the project I will not use people's names (unless they want me to, for example to be credited as a young researcher). Recordings, transcripts and personal information will be kept in a secure filing cabinet, or a password-protected computer.

What will happen if I don't want to carry on with the project?
You can stop being involved in the project at any time by contacting Louca-Mai and letting her know.

How do I take part in this project?
If you are happy to take part in the project, please complete the enclosed consent form and return it to Louca-Mai. When Louca-Mai receives the consent form she will contact you to talk about what happens next.

Contact for further information?
If you have any questions about the project, please speak to the person who gave you this information or contact the Louca-Mai by e-mail at: louca.brady@uwe.ac.uk or call or text her on xxx

Embedding children and young people's participation in the Community Children's Health Partnership

Information sheet for adult participants

Background

My name is Louca-Mai Brady and I am doing a PhD at the University of the West of England on 'embedding children and young people's participation in health and social care service settings'. As part of my PhD research I will be working with North Bristol NHS Trust (NBT) and Barnardo's HYPE project to explore children and young people (CYP)'s participation within and across the Community Children's Health Partnership (CCHP), and what is required for this participation to be meaningful, effective and sustained at individual, service and strategic levels.

Aims of the project

The project aims to answer the following questions:

- How is CYP's participation understood and put into practice?
- What does it mean to 'embed' CYP's participation?
- What needs to be in place for participation to be meaningful, effective and sustainable - at different levels, for different groups and in different settings?
- What are the barriers and challenges to meaningful, effective and sustainable participation and how can these be addressed?

What will be involved?

From September 2013 I plan to spend up to a year working with two case studies: the CCHP and a research project working with young people who have misused alcohol and drugs. I will be taking an action research approach, which involves using cycles of action and reflection to facilitate change.

I hope that CCHP and HYPE staff and young people will be actively involved throughout the year as project stakeholders, and early on the process we'll be looking at who wants to be involved and how this could happen. The exact nature of this process will be determined by what is most useful to the CCHP, and also by when and how individual adults and young people are available and able to be involved. But the case study is likely to involve me attending some existing meetings and groups to explore current practice, alongside an on-going series of inquiry workshops where we will explore your experiences of participation, and identify and act on areas for action and change. If we decide it would be useful I may also collect some information from NBT staff, other professionals and young people who are not project stakeholders, for example through interviews and focus groups.

Consent

If you agree to be involved in the project you will be asked to sign a consent form, but you will have the right to withdraw from involvement in the project at any time without prejudice and without providing a reason. If the nature of your involvement changes as the project develops, we will also review and update your consent as felt necessary by the researcher, NBT and/or when you request it.

Confidentiality, safeguarding and data protection

Some meetings, workshops, groups and interviews will be digitally recorded and transcribed, but consent will be sought for this beforehand. All data (including written output from workshops and groups) will be anonymised and stored securely in accordance with data protection requirements and the UWE and NBT data protection procedures. I have also addressed issues of confidentiality, safeguarding and data protection in depth in my submissions to NBT QICA and UWE faculty REC (see below), and have enhanced CRB clearance. Further information on data protection processes and data management plans are available for all participants on request.

Where project stakeholders will have access to data (eg when we're working together to review learning from one phase of the project in order to plan next steps) there will be clear agreements about confidentiality, and any data will be anonymised before being shared. Sensitive information will not be shared collaboratively without explicit consent from the person or service it relates to. Any written outputs will not contain information with which it would be possible to identify individuals. If stakeholders are involved in data collection as part of their work on the project they will be briefed and supported on relevant aspects of research ethics, including informed consent and confidentiality.

About the researcher

I have a background in research with CYP; health, public health and social care; disability; patient and public involvement and participative research (including most recently as a senior researcher at the NCB Research Centre, where I led their work on the involvement of CYP in research). I am also a member of INVOLVE , the national advisory group that supports greater public involvement in NHS, public health and social care research.

Ethics

The National Research Ethics Service and NBT Research and Innovation have assessed this project as not requiring NHS research ethics committee approval. This project has therefore been approved by the NBT Quality Improvement & Clinical Audit (QICA) department and UWE's Health and Life Sciences Faculty Research Ethics Committee.

For further information

If you have any questions about what taking part in this project will involve, or would like more information, please email me at: louca.brady@uwe.ac.uk.

Embedding children and young people's participation in health services and research

Information sheet for YSBNT adult participants

Background

My name is Louca-Mai Brady and I am doing a PhD at the University of the West of England on 'embedding children and young people's participation in health services and research'. From September 2013 I will be spending up to 18 months working with two case studies: the 'Youth Social Behaviour and Network Therapy ' (YSBNT) study and a children's community health partnership. The focus of the YSBNT case study will be on public involvement, and specifically how YP with experience of using drug and alcohol services can be involved in a study of this nature, and how learning from the study informs plans for YP's involvement in a possible full trial and contributes to the wider evidence base on public involvement in health research.

Aims of the project

The project aims to answer the following questions:

- How is CYP's participation[1] understood and put into practice?
- What does it mean to 'embed' CYP's participation?
- What needs to be in place for participation to be meaningful, effective and sustainable - at different levels, for different groups and in different settings?
- What are the barriers and challenges to meaningful, effective and sustainable participation and how can these be addressed?

What will be involved?

I am taking an action research approach, which involves using cycles of action and reflection to facilitate change. The exact nature of this process will therefore be determined in consultation with those involved and also by when and how individual adults and young people are available and able to be involved. But the case study is likely to involve informal discussions at existing meetings and groups as well as more formal inquiry workshops or focus groups, for which consent will be sought.

Consent

If you agree to be involved in contributing to formal data collection (for example by participating in a focus group discussion) you will be asked to sign a consent form. However you will have the right to withdraw from involvement in the project at any time without prejudice and without providing a reason. If the nature of your involvement or contribution to the project changes this consent will be reviewed and updated as felt necessary by the researcher, BSMHFT and/or participants.

[1] The research takes place in the wider context of children and young people's participation, so this is the term used in the wider research questions, but this particular case study focuses on 'patient and public involvement' as this is the terminology used within health research and NIHR. For the purposes of this document please regard the terms as synonymous.

Confidentiality, safeguarding and data protection

If discussions are to be used as data they will digitally recorded and transcribed and consent will be sought for this beforehand. All data (including written output from workshops and groups) will be anonymised and stored securely in accordance with the terms and conditions of the 1998 Data Protection Act and the UWE data protection procedures. I have also addressed issues of confidentiality, safeguarding and data protection in depth in my submissions to UWE faculty REC (see below), and in correspondence with BSMHFT before this project commenced, and have enhanced CRB clearance. Further information on data protection processes and data management plans are available for all participants on request.

Where project stakeholders will have access to data (eg when we're working together to review learning from one phase of the project in order to plan next steps) there will be clear agreements about confidentiality, and any data will be anonymised before being shared. Sensitive information will not be shared collaboratively without explicit consent from the person or group to which it relates.

About the researcher

I have a background in research with children and young people; health, public health and social care; disability; patient and public involvement and participative research (including most recently as a senior researcher at the NCB Research Centre, where I led their work on the involvement of CYP in research). I am also a member of INVOLVE, the NIHR advisory group that supports greater public involvement in NHS, public health and social care research.

Ethics

The National Research Ethics Service has assessed this project as not requiring NHS research ethics committee approval. This project has therefore been approved by BSMHFT and UWE's Health and Life Sciences Faculty Research Ethics Committee.

For further information

If you have any questions about what taking part in this project will involve, or would like more information, please email me at: louca.brady@uwe.ac.uk.

Youth Social Behaviour and Network Therapy Study
Young Advisors – Application and Consent Form

Birmingham and Solihull Mental Health Foundation Trust are looking for young people who have experience of using drug and alcohol services between the ages of 12 and 18, to become Young Advisors for the Youth Social Behaviour and Network Therapy (Y-SBNT) Study.

If you have read and understood the information sheet and role description please fill in this consent form so that we know you are interested in taking part. If you need help with any of the questions, or need this form in a different format, please ask the person who gave you this or contact Louca-Mai Brady (see details at the end of the form).

The deadline for submitting this form is **Wednesday 31st July.**

Note: please also ensure your parent/guardian/carer gives permission for you to take part by signing and filling in their details at the end of this application.

All personal information will be kept securely, and your form will only be seen by people working with the young advisors group.

Personal Details

First name: Surname:

Address:

Home telephone number:

Mobile number:

Email:

Age:

Date of birth:

Are you: Male: ☐ or Female: ☐ *(please tick)*

Please tick the box below that best describes your ethnic origin:

White	Mixed	Asian or Asian British	Black or Black British	Chinese or other ethnic group
British ☐ Irish ☐ Other White background ☐	White & Black Caribbean ☐ White & Black African ☐ White and Asian ☐ Other Mixed background ☐	Indian ☐ Pakistani ☐ Bangladeshi ☐ Any other Asian background ☐	Caribbean ☐ African ☐ Any other Black background ☐	Chinese ☐ Any other ethnic group ☐

Have you used drug and alcohol services in the past?
☐Yes ☐No

How old were you when you started using drug and alcohol services? ……..

How old were you when you stopped using drug and alcohol services? ……

Do you consider yourself to belong to any of these groups?
☐ In or leaving care
☐ Young carer
☐ Refugee or asylum seeker
☐No I don't belong to any of these groups

About you

Looking at the information we've given you about the project, why are you are interested in becoming a Y-SBNT young advisor?	

Is there any help and support that you think you will need from the adults who are working with the group (e.g access or other support)?

The first meeting of the young advisors group will be in London on **Monday 12th August.** Can you come to this meeting?

☐Yes ☐No ☐ I'm not sure

Consent

I have read the letter and information leaflet about the Y-SBNT study. I understand what the study is about and what I will be involved in.

Yes ☐ No ☐

I know that I can decide to stop being involved in the project at any time

Yes ☐ No ☐

I understand that if I am accepted as a member of the young advisors group I will need to come to least four of six meetings in Birmingham between August 2013 and August 2014, as well as 2-3 meetings a year in the following two years.

Yes ☐ No ☐

I understand that being involved in the young advisors group will also involve some work which Louca-Mai Brady will use for her PhD research at the University of the West of England, and I am happy for any work we do as a group to be used for this purpose

Yes ☐ No ☐

Photo consent
We may want to use photos or images taken during work with the young advisors group. The images may also be used to tell show people what the group has done and evaluate the project. We will not normally identify individuals. Are you happy for us to take photographs or other images from time to time, providing we ask your permission before using them?
Yes ☐ No ☐

Travel to meetings
Are you happy to travel to and from meetings on your own, or will a parent or carer go with you?
I will travel on my own ☐ I will travel with my parent or carer ☐

DECLARATION: I would like to be part of the Y-SBNT young advisors group and am willing to accept the responsibilities in 'consent' above	
Signed	
Print Name	
Date	

PARENT/CARER CONSENT:
Please get a parent/guardian to complete the boxes below:

I have read and understood the accompanying letter and information leaflet and give permission for the young person (named above) to become a Y-SBNT Research Advisor. I have checked and confirmed the correctness of the information provided above.	
Signed	
Print Name	
Relationship to person seeking consent	
Contact phone number	
Contact email address	
Date	

Please return this form in the freepost envelope provided to:
or email back to xxx

THANK YOU!

Children and Young People's CCHP Participation Project
Young People - Consent Form

Louca-Mai Brady is doing a project at the University of the West of England on how children and young people are involved in health and social care services. As part of this project she will be working with North Bristol NHS Trust (NBT) and Barnardo's HYPE project to find out about children and young people's involvement in the Community Children's Health Partnership (CCHP) through things like staff recruitment, training and other ways in which young people help make CCHP services better. Louca-Mai would like to work with young people aged 12-18 who have been involved in the CCHP and HYPE and are interested in helping her with this project.

If you have read and understood the information sheet please fill in this consent form so that we know you are interested in taking part.

The deadline for submitting this form is **……**

Note: please also ensure your parent/guardian/carer gives permission for you to take part by signing and filling in their details at the end of this application.

All personal information will be kept securely, and your form will not be seen by anyone apart from Louca-Mai.

Personal Details

First name: Surname:

Address:

Home telephone number:

Mobile number:

Email:

Age:

Date of birth:

Are you: Male: ☐ or Female: ☐ *(please tick)*

Please tick the box below that best describes your ethnic origin:

White	Mixed	Asian or Asian British	Black or Black British	Chinese or other ethnic group
British ☐ Irish ☐ Other White background ☐	White & Black Caribbean ☐ White & Black African ☐ White and Asian ☐ Other Mixed background ☐	Indian ☐ Pakistani ☐ Bangladeshi ☐ Any other Asian background ☐	Caribbean ☐ African ☐ Any other Black background ☐	Chinese ☐ Any other ethnic group ☐

Do you consider yourself to belong to any of these groups?
☐ In or leaving care
☐ Young carer
☐ Refugee or asylum seeker
☐No I don't belong to any of these groups

About you

How have you been involved in the CCHP (eg have you been involved in recruitment, training or other activity)?

Why are you interested in being involved in this project, and how would you like to be involved?

Is there any help and support that you think you will need from the adults who are working with the group (e.g access or other support)?

Consent

I have read the letter and information leaflet about the CCHP participation project. I understand what the study is about and the part I will be involved in.

Yes ☐ No ☐

I know that I can decide not to continue with my involvement in the project at any time.

Yes ☐ No ☐

Photo consent
We may want to use photos or images taken during work with the young advisors group. The images may also be used to tell show people what the group has done and evaluate the project. We will not normally identify individuals. Are you happy for us to take photographs or other images from time to time, providing we ask your permission before using them?
Yes ☐ No ☐

Travel to meetings
Are you happy to travel to and from meetings on your own, or will a parent or carer go with you?
I will travel on my own ☐ I will travel with my parent or carer ☐

DECLARATION: I would like to be part of the CCHP participation project and am willing to accept the responsibilities in 'consent' above	
Signed	
Print Name	
Date	

PARENT/CARER CONSENT:
Please get a parent/guardian to complete the boxes below:

I have read and understood the accompanying letter and information leaflet and give permission for the young person (named above) to be involved in the CCHP participation project. I have checked and confirmed the correctness of the information provided above.	
Signed	
Print Name	
Relationship to person seeking consent	
Contact phone number	
Contact email address	
Date	

Please return this form to the person who gave it to you or email back to louca.brady@uwe.ac.uk

THANK YOU!

CONSENT FORM

Title of Project: Embedding children and young people's participation in health and social care service settings

Name of Researcher: Louca-Mai Brady

Please initial all boxes

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason ☐

3. I understand that direct quotes may be used when the project is written up, although they will be anonymised ☐

4. I agree to group discussions in which I participate being audio-taped ☐

5. I agree to take part in the above study ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 copy for participant; 1 copy for researcher

CONSENT FORM: YSBNT TMG/TSC FOCUS GROUPS

Title of Project: Embedding children and young people's participation in health services and research

Name of Researcher: Louca-Mai Brady

Please initial all boxes

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions ☐

2. I agree to take part in the above study ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason ☐

4. I agree to the focus group discussion in which I participate being audio-taped and transcribed ☐

5. I understand that direct quotes from focus group discussions may be used when the project is written up, although they will be anonymised ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 copy for participant; 1 copy for researcher

Appendix 4: Ethical approval

University of the West of England
BRISTOL

Faculty of Health & Life Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

Our ref: JW/lt

9th July 2013

Louca-Mai Brady

Dear Louca-Mai

Application number: HLS/13/06/88
Application title: Embedding children and young people's participation in health and social care service settings

Your ethics application was considered by the Faculty Research Ethics Committee and based on the information provided was given ethical approval to proceed with the following conditions:

1) Slight rewording on information sheets:

- first case study consent form (CCHP) define 'participation' (even though this was already explained on the excellent information sheet), and in second sentence change 'my' to 'her';
- in the adult info sheet (CCHP) define 'embed'
- in young advisors' application and consent form consider replacing the double negative 'your form will not be seen by anyone who is not working with the young advisor's group' with the more straightforward 'will only be seen by people working with the young advisors group'.

2) Clarify how issues of confidentiality and anonymity would be addressed in the case of blogs and social media

If these conditions include providing further information please do not proceed with your research until you have full approval from the committee. You must notify the Faculty Research Ethics Committee in advance if you wish to make any significant amendments to the original application.

If you have to terminate your research before completion, please inform the Faculty Research Ethics Committee within 14 days, indicating the reasons.

Please notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Any changes to the study protocol, which have an ethical dimension, will need to be approved by the Faculty Research Ethics Committee. You should send details of any such amendments to the committee with an explanation of the reason for the proposed changes. Any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

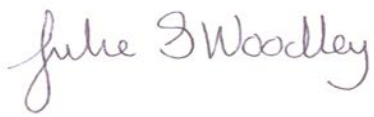
Please note that all information sheets and consent forms should be on UWE headed paper.

Please be advised that as principal investigator you are responsible for the secure storage and destruction of data at the end of the specified period.

Please note: The University Research Ethics Committee (UREC) is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely



Dr Julie Woodley
Chair
Faculty Research Ethics Committee

c.c Barry Percy-Smith

Appendix 5: Example CCHP session plans and topic guides

CCHP – Developing a Participation Strategy: workshop 2
Thursday 7/11/13, 9.30-12.30

Session plan

Venue: xx

Set up: Circle/small groups of chairs **Resources:** see end of document

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Resources: Name labels, flipchart + paper & pens, notes from last meeting

9.30am Check-in, coffee/tea

9.35am Welcome & introductions

9.45am Update: run through notes from last time. Are these a fair reflection? Any comments or questions? Update on CYP meeting and parents focus group + plans to do focus group with OM and CG meetings

Give people a chance to look at YP flipcharts and say will come back to later when thinking about values

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10.00 Starting point: children's rights and the UNCRC

Resources: flipchart with UNCRC articles, general comment handout, flipchart paper, blu-tack, pens, sellotape/glue.

Very brief refresher on children's rights and the UNCRC (5 mins)

Give out CRC General Comment. **In small groups** spend a few moments discussing this and then stick it in the middle of a piece of flipchart paper. Annotate to indicate what you think is particularly relevant to the embedding of participation in the CCHP/our strategy and add any comments or ideas (15 mins)

Group discussion: feed back. Will come back to again when think about values (10 mins)

10.30 Practice – what can we use?

Resources: flipchart paper, blu-tack, pens, post-its. Posters of various participation models and tools around the room, flipcharts from YP meeting

Models and tools – how did everyone get on with these? (5 mins)

Picking up from our last meeting: take a pack of post-its and spend some time going round and reflecting on what's on the posters, getting some general impressions from models and tools and consider in light of your reflections & our discussions:

- What is useful/not useful about this model or tool?
- How are these relevant or not to embedding CYP's participation in the CCHP/your service?

Add comments and questions to the posters with your post-its. We will come back to these at the next workshop (15 mins)

10.20: Collective reflection on poster exercise

- How are these models and tools relevant or not to embedding CYP's participation in the CCHP?
- What issues or questions do they raise and do they challenge your experience of current participation values and practice within the CCHP?
- Are there some, or elements of some that we could use to support embedding CYP's participation in the CCHP? Or do we want to start with a 'blank sheet'? (10 mins)

11.00 Structure – what do we have? (*short break at convenient point during this session)

Resources: flipchart paper, pens, notes from last meeting, spare copies of map

Look at the map [Participation manager] has developed of CCHP participation following our discussions last time (back page of notes from last workshop). Are we happy with this? Any changes or amendments? (5-10 mins) Point out key enablers/facilitators, gaps and areas needing attention (10-15 mins)

Whole group discussion: What does this exercise tell us about the infrastructure for the embedding of CYP's participation in the CCHP? Any points we need to think about in future meetings with regards to the planning, development and resourcing of participation? (10 mins)

11.30 Culture

Resources: flipchart paper, pens, notes from last meeting, handouts - CCHP values

A working definition: the terms values, principles and standards have been used in different ways, and in some cases they have been used interchangeably. But in a recent INVOLVE document they were defined as:

- Values – overarching ideals
- Principles – statements that describe those ideals in more detail, providing further information and potentially some context
- Standards – the operationalisation of principles, giving a clear idea of the agreed way to involve CYP and allowing assessment to take place

What do you think about these definitions? Could they be useful to inform a strategy?

Thinking back to the values we generated last time, the ideas that came from the YP's meeting and also looking at the values of CCHP: how do we want to agree the values and principles that will underpin our strategy (could do individually or in small groups)? Could then finalise these and look at standards with YP next time

---

12.00 Review and next steps (*lunch available)

12.10: Review: How will we turn all the ideas from these workshops into a strategy? What should this look like? How will we know if it's working? Who should do it and how?

12.20: Planning for action: what we want to do before and during the final meeting in this cycle, which will be with the young people involved in the project

12.30 Close

CCHP – Developing a Participation Strategy: YP workshop 1
Wednesday 22/10/13, 4-6pm

Session notes

Venue: xx
Set up: Circle/small groups of chairs **Resources:** see end of document

---

Resources: Name labels, flipchart + paper & pens.

16.00 Check in
16.05 LM: **Welcome + introduce self.** *Give out information sheets and consent forms & get verbal agreement to record group discussions. Explain that will give out vouchers at the end of the meeting*
16.10 All: **bus stop introductions** (2 mins) - who you are, how you've been involved in the CCHP, why you wanted to come to this workshop and one interesting fact about yourself (that willing to share!)
Agree ground rules for the meeting

16.20 What is participation?
Resources: photovoice pictures laid out on table, flipchart paper, blu-tack, coloured pens, stickers & other art materials

Before we start talking about this project, one of the ways in which we can see things differently is by using images rather than words. So will start of our work today by using by pictures as metaphors
Choose a photo that captures something about what CYP's participation means to you, in the CCHP or more generally

Select a photograph spontaneously & quickly – don't think about what you want to say and find a picture to match but just let yourself be drawn to a photograph
Then go back to small groups and begin a conversation around your photos – reflect on the ideas being shared and then summarise the key values. Capture the main threads of your conversation on the flipchart paper, blu-tacking the pictures on and using other materials if this is helpful – what do the pictures you have chosen/your ideas have in common? How are they different? (20 mins)

Group feedback: What does participation mean – to you, to services, to the CCHP? What things do you think are most important to help CYP participate? (10 mins)

16.45 LM: **The project**
Resources: flipchart, information sheets, consent forms, CCHP process handout

Why we're here (brief background to project and plans for involving YP)
Talk through information sheets, ask to sign consent forms & talk through research process & action research process diagrams. The focus of this project is on us all working together to learn from what's working well in CYP's participation in the CCHP and think about how we can make things better.
Questions/comments?

Update on 1st staff workshop: People who work for the CCHP talked about what participation meant to them, where they thought it was happening and started to think about how we could do it (tools, resources) and what we needed to do to make participation as good as possible right across the CCHP (strategy)
Met parents this lunchtime and meeting staff again on 7/11, where I'll talk to them about what you all said in this group. Then planning to bring this and staff group together on **Thursday 5th December 4-6.30pm** if that works for this group too. At this last meeting we'll decide on a strategy and also what happens next in the project.

Will have a chance to agree what happens next at the end, but any questions now?

17.00 'Good participation'

flipchart paper, blu-tack, coloured pens, stickers & other art materials

Group discussion: *what do you think 'good' participation might mean for you, other CYP who are or could be involved?* Explain/explore what these words might mean: good vs bad (5 mins)

In small groups:
Using flipchart paper, pens and other materials, map out or draw what you think 'good' participation might look like. You could do this just by writing, doing a mind map, drawing (eg if good participation was an animal/building what would it look like?) (10 mins)

Whole group discussion: What do you think are the most important things we need for good participation in the CCHP? What could it mean to 'embed' participation (meaningful, effective, sustained *Prioritise top ten and get YP to vote?* (10 mins)

17.25 What happens next?
As this project is all about CYP's participation really important that YP are involved during the research.

What do you want me to feed back to the next staff workshop on 7/11?
Do you want to be involved in the project and if so how (ie when and how meet – face-to-face and/or online)?
What do you think about how this group could work?
Do you want to come to meet with staff on 5/12?

17.40 Give out vouchers/ pay travel expenses

17.45 Finish

RESOURCES:
Supplied by Barnardos: 2-3 flipchart & paper, pens, blu-tac (art materials?)
LM to bring:

- Digital recorder
- Stickers for name labels
- Project information sheets & consent forms
- Receipt forms for vouchers and expenses
- CCHP AR model
- Photovoice pictures
- Stickers & post-its

Notes for Physio workshop 3 15/7/14

2– 2.30pm: INTRODUCTIONS, NOTES FROM LAST MEETING, UPDATES ON ACTIVITY (30 mins)

Agenda, notes from last meeting

2.30-3.10pm: Reflections

Reminder of AR cycle (ref handouts)

Prompts (write on flipchart):

- What have we learnt about the reality of embedding children and young people's participation in services? What do we think 'embedding participation' means in practice?
- How have the draft strategy and framework informed this, and how will this work inform them and their implementation?
- What has helped or facilitated?
- What has hindered/created challenges? What are the gaps? How have or could these be addressed?

Flipcharts around room with 'embedding participation in practice', 'links to and from strategy and framework', 'what helps/faciltates', 'challenges and gaps' and 'any other comments'.
-Get people to write down ideas on post-its and stick on most appropriate flipchart (10 mins)
- Go round and look at what people have written (10 mins)
- Group discussion (15 mins)

AR handouts, flipchart paper, pens, blutack, post-its

3.10-3.40pm: Taking the work forward

Going back to the four elements of the whole systems approach to participation, how could we take this work forward across CCHP? Refer to activity handout and strategy/framework

Divide into four groups – each to start with different element and move onto others if they have time (15 mins)

Group discussion (15 mins)

Whole systems handout, strategy, framework, flipcharts and pens

- **3.40-4pm: Planning for action:**

  - *As per agenda, and diagram in notes from last meeting,* what happens next…
    a) In Physio team?
    b) In project?
  - What will be needed to make this happen?
  - How would you like to be involved? *Who wants to be involved in workshop in autumn?*

Reflections on process – how have people found these workshops/this work? What has worked well? What could we have done better/differently?

Flipcharts and pens

Embedding Children and Young People's Participation in the CCHP - Topic guide for parent focus group 23/10/13

Aim of the group: to explore parent's experience of children and young people's involvement in the CCHP and their perceptions of the role of parents in enabling this and what it means to 'embed' participation in the CCHP

Who will be interviewed: 5 parents – all with experience of being involved in participation projects, mainly recruitment of CCHP staff, Participation training and Pathway audits

Start

- Introduce self
- Introduce the study. Explain that:
    - it will focus on your own experience of participation in the CCHP
    - recognise that not everyone will be able to comment on every topic
- Give out and talk through information sheets and consent forms
- Check it's OK to digitally record, and reassure re: confidentiality
- Reminder of group length – (1.5 hour approx)
- Any questions/concerns?

Introduction

- **Photo exercise:**

Before we start talking about this project, one of the ways in which we can see things differently is by using images rather than words. So will start of our work today by using by pictures as metaphors

Choose a photo that captures something about what CYP's participation means to you, in the CCHP or more generally. Select a photograph spontaneously & quickly – don't think about what you want to say and find a picture to match but just let yourself be drawn to a photograph

- **Introductions.** Who you are, how you've been involved in the CCHP, why you wanted to come to this group and something about the photo you've chosen

Understanding participation

What does participation mean – to you, to young people to services, to the CCHP?

Do you think it's important? If so why?

Role of parents/carers

How have you been involved in participation?
How do you think parents & carers could/should be involved? Are there some CYP who need more parental support than others to have their voices heard?
Should parents & carers role be to support CYP's participation or should they have a say in their own right? Or both?

Embedding participation

What do you think 'good' participation looks like – for YP, parents/carers, staff, services, organisations and nationally?

What needs to be in place for participation to be embedded? How can it be meaningful/ effective/ sustained? What values should be central to CYP's participation?

How can we measure the impact of participation?

Participation in the CCHP

What does participation in the CCHP look like at the moment?

What is good about it?

Are there gaps or areas for improvement?

How could participation best be 'embedded' in the CCHP? What do you think should be included in a CCHP participation strategy?

Any comments on suggestions on the project itself/who I should be talking to/future involvement of parents?

Summary and close:

- Anything else that the participants think is important?
- Any questions?
- Reassure again regarding confidentiality and publication plans.

Thank you.

Embedding Children and Young People's Participation - Topic guide for CCHP commissioners focus group

Aim of the session: to explore commissioners experience of children and young people's involvement in the CCHP and their perceptions of the role of commissioners in enabling this and what it means to 'embed' participation in the health and social care service design and delivery

Who will be involved: attendees at CCG meeting, of which this will be a 30-min agenda item

Start

- Introduce self
- Remind people about the study with ref to presentation at last meeting. Explain that:
    - it will focus on their own experience or views of CYPs participation
    - recognise that not everyone will be able to comment on every topic
- Give out and talk through information sheets and consent forms
- Check it's OK to digitally record, and reassure re: confidentiality
- Reminder of discussion length – (30 mins)
- Any questions/concerns?

Understanding participation

What does participation mean – to you, to the services you commission, to the CCHP?

Do you think it's important? If so why?

Role of managers

How have you been involved in participation?
How do you think commissioners could/should be involved?

Embedding participation

*What do you think 'good' participation looks like – for YP, parents/carers, staff, services, organisations and nationally? (*optional: *Should parents & carers role be to support CYP's participation or should they have a say in their own right? Or both?)*

What needs to be in place for participation to be embedded? How can it be meaningful/ effective/ sustained? What values should be central to CYP's participation?

How can we measure the impact of participation?

Participation in the CCHP

What does participation in the CCHP look like at the moment?

What is good about it?

Are there gaps or areas for improvement?

How could participation best be 'embedded' in the CCHP? What do you think should be included in a CCHP participation strategy?

Any comments on suggestions on the project itself/who I should be talking to/future involvement of this group/other CCHP managers?

Summary and close:

- Anything else that the participants think is important?
- Any questions?
- Reassure again regarding confidentiality and publication plans.

Thank you.

Appendix 6: Example notes from CCHP workshops

CCHP STAFF PARTICIPATION WORKSHOP 1 - 26TH SEPTEMBER 2013

Background

This document summarises the discussions of the first of a series of three workshops facilitated by Louca-Mai Brady, a researcher from the University of the West of England who is doing a project on 'embedding children and young people's participation in health and social care services'. She will be working with CCHP from September 2013 to the autumn of 2014 to explore existing assumptions and practices around participation, and what is required for children and young people (CYP)'s participation to be embedded effectively.

The project is taking an action research approach, outlined further below, through a series of workshops and other activities. This first series of three workshops is focusing on developing a CCHP participation strategy, and further series of workshops will then explore how this strategy can be used to support the embedding of participation.

This first workshop was structured around a **whole-systems approach to participation** (Social Care Institute of Excellence, Practice Guide 11, 2006[1]), which has four elements that we'll consider during these workshops:

Culture – Ethos of an organisation shared by all staff and services users which demonstrates a commitment to participation.

Structure – The planning, development and resourcing of participation evident in organisation's infrastructure, with key staff, roles and resources identified for its implementation.

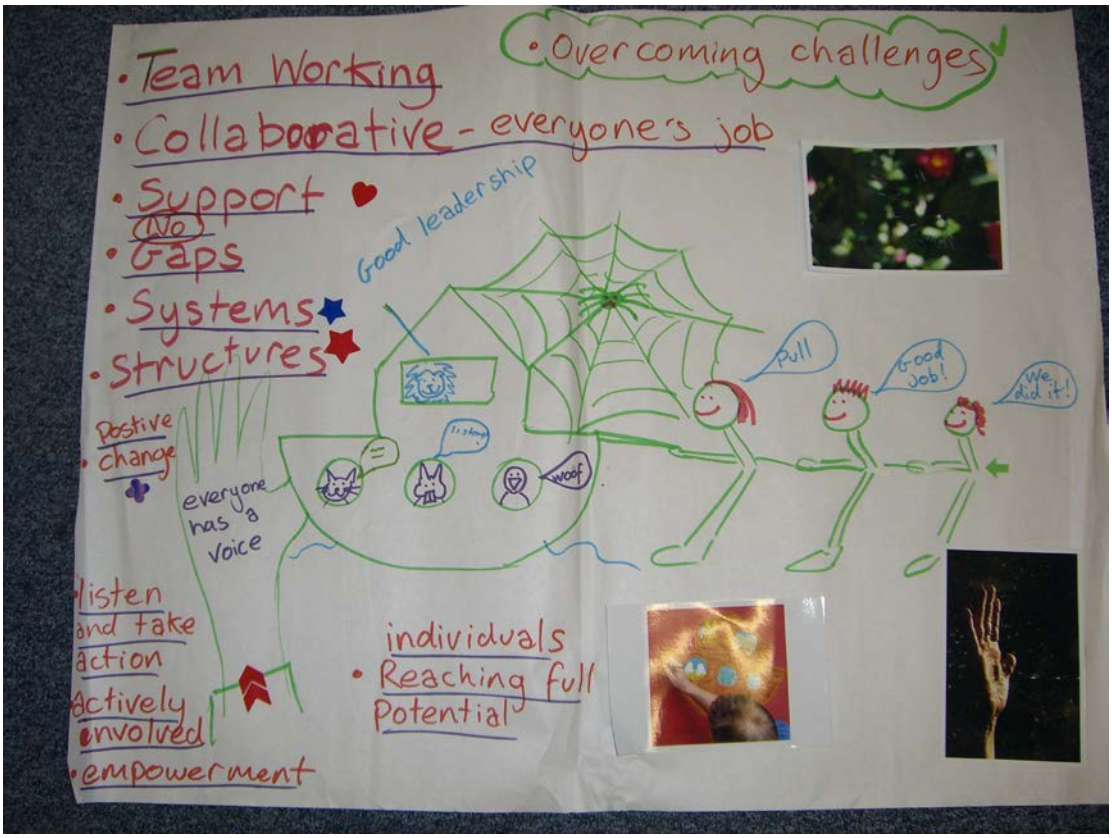
Practice – The way of working, methods of involvement, skills and knowledge which enable children and young people to become involved.

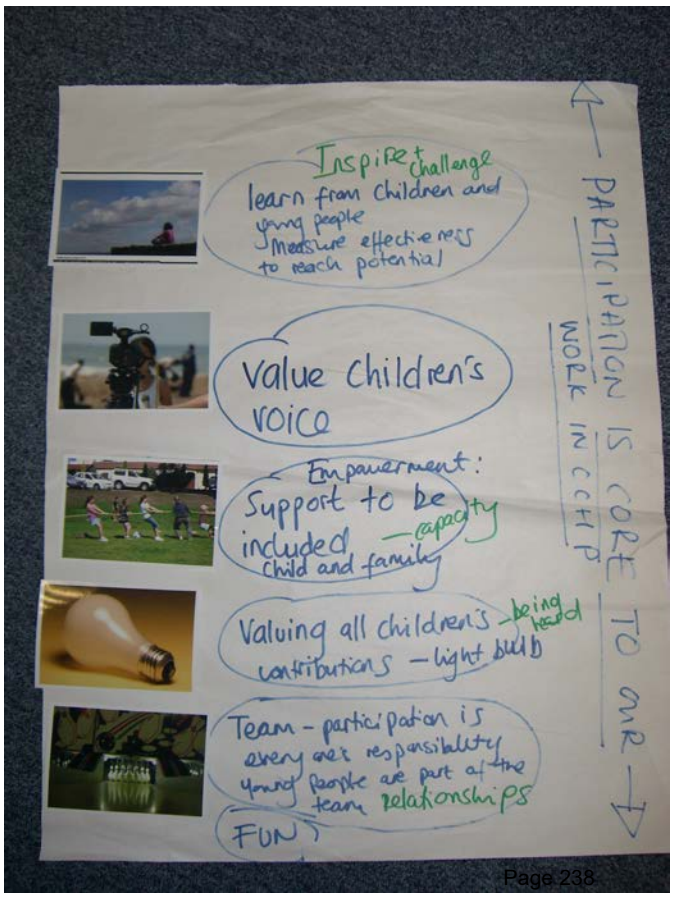
Review - The recording, monitoring and evaluation systems which enable an organisation to evidence change affected by participation. This should be shared within the organisation, with partners and the commissioners.

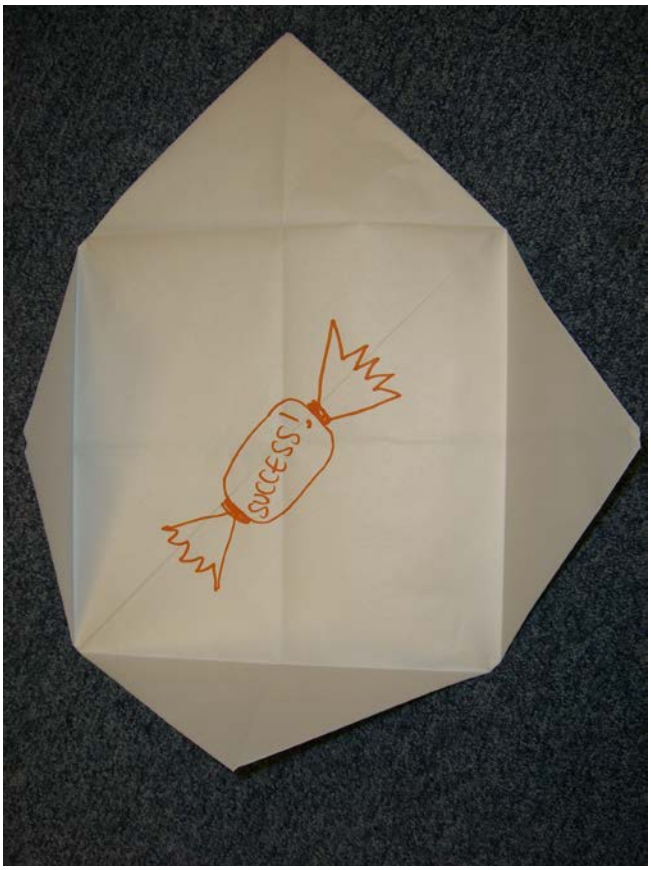
[1] http://www.scie.org.uk/publications/guides/guide11/

CULTURE

We started off the day by exploring culture and shared values in CCHP around CYP's participation. Everyone selected a photo that they felt captured something about the values they felt were central to participation and then in small groups came up with creative ways to express these ideas:







Flipchart notes from values discussion

- Participation should be fun
- But also collaborative learning: from others, professionals, families, children and young people. Sharing practice and linking up
- Measuring / demonstrating impact / evidence / feeding back to children and young people / families
- Participation is an intrinsic part of role not an add on
- Universal system
- Owned by everyone / everybody's job
- Whole system approach
- Structures and systems need to support values
- Empowerment / people
- reaching their full potential
- change that is significant to individuals involves as well as wider service / organisation
- good leadership – link to structures and systems
- everyone has a voice
- working collaboratively
- listening / valuing children's voice

- participation needs to be inspired and challenging
- People can express voice in different ways
- People need support to be included and to be empowered) including building capacity through knowledge and skills)
- valuing all contributions

BACKGROUND

Louca-Mai then gave some background to the project (see information sheet) and we discussed the fact that, although the case for CYP's participation is well-documented, there is little evidence on how to 'embed' this participation – especially in health and social care services. CCHP is held up as a national exemplar of how collaborative working can support participation, and therefore this project will explore how to build on this and ensure that participation in the CCHP is meaningful, effective and sustained.

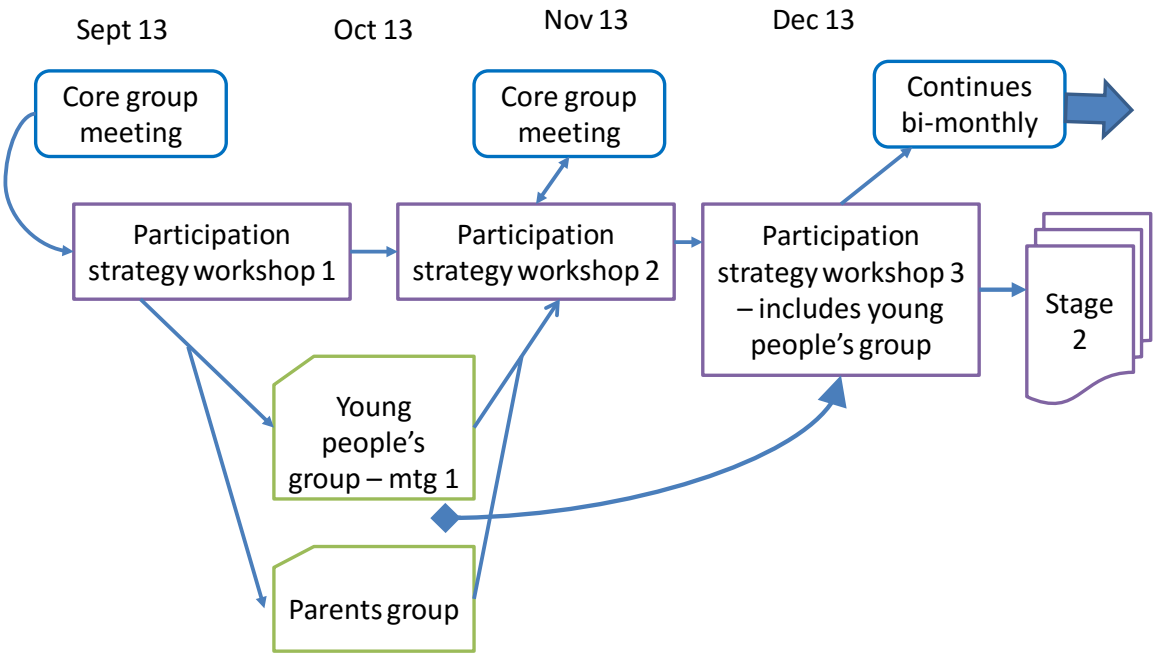
Louca-Mai then gave a brief introduction to **action research**, the process we'll be using during this project, which involves an iterative process of learning for change a spiral of self-reflective cycles of:

- Planning a change
- Acting and observing the process and consequences of the change
- Reflecting on these processes and consequences and then replanning
- Acting and observing
- Reflecting
- Planning a change …

Action research is a process of collaborative learning for change, a reflective and systematic inquiry to challenge and change assumptions and practice. Through looking critically (inquiry) new understanding is developed which provides new possibilities for action and change. The purpose is to work collaboratively towards practical outcomes by supporting the development of new forms of understanding. So it is not just about identifying solutions to immediate problems but also reflecting on and learning from intended and unintended outcomes.

We discussed how using an action research approach will enable us to open up to critical inquiry existing assumptions and practices around participation in the CCHP, and develop thinking about the systems and processes needed for CYP's participation to be embedded effectively. This first cycle is illustrated below, with these workshops on the second line in the purple boxes:

CCHP – Stage 1: Process



We then discussed the terminology around participation, involvement and engagement, and agreed on a **working definition of participation** for the project:

> *A process and culture in which children and young people are listened to, their opinions are respected and they are actively involved in decision-making which brings about change in themselves, their peers, the services they use and their communities*

Going back to culture, structure, practice and review (see p1) we then looked at:

STRUCTURE

Thinking back to the values we generated earlier, we started to critique existing arrangements and identify gaps and areas needing attention. In small groups people mapped out the key staff, roles and resources involved in implementation of CYP's participation in the CCHP, and then discussed these in relation to a map developed by [Participation Manager] prior to the meeting (see appendix).

Action: [Participation Manager] to incorporate additions into a revised map, which we'll all consider at the next workshop in relation to the infrastructure needed for the embedding of CYP's participation in the CCHP

PRACTICE

For the final part of the workshop we started to look at various participation tools and models, which were stuck on the walls around the room. These included Hear by Right[2], Young People Friendly[3] and others saved in the Google docs folder. The idea was to get some general impressions about whether and how are these were useful and relevant (or not) to embedding CYP's participation in the CCHP. However as time was getting tight it was agreed that actions for our next workshop would be:

Actions:
Louca-Mai to set up Google group for project and create a folder for all the models and tools
All to then have a look at these before the next workshop and consider how they could be used in your service(s), what issues or questions do they raise and if and how they challenge your experience of current participation values and practice in the CCHP?

Next steps

We finished the workshop by 'planning for action'. Louca-Mai asked 'what actions or changes do you feel should be a priority for us to develop a participation strategy for the CCHP' and people suggested the action above re: thinking about how the models and tools could be applied to their work and CCHP more generally.

Louca-Mai informed the group that she would be presenting on the project at the Operational Management group later that day, and also getting their views and those of the Clinical Governance group on CYP's participation in the CCHP. She also outlined plans for consulting parents (through a focus group on 23/10) and young people (through a first meeting with a group of YP involved in CCHP participation also on 23/10).

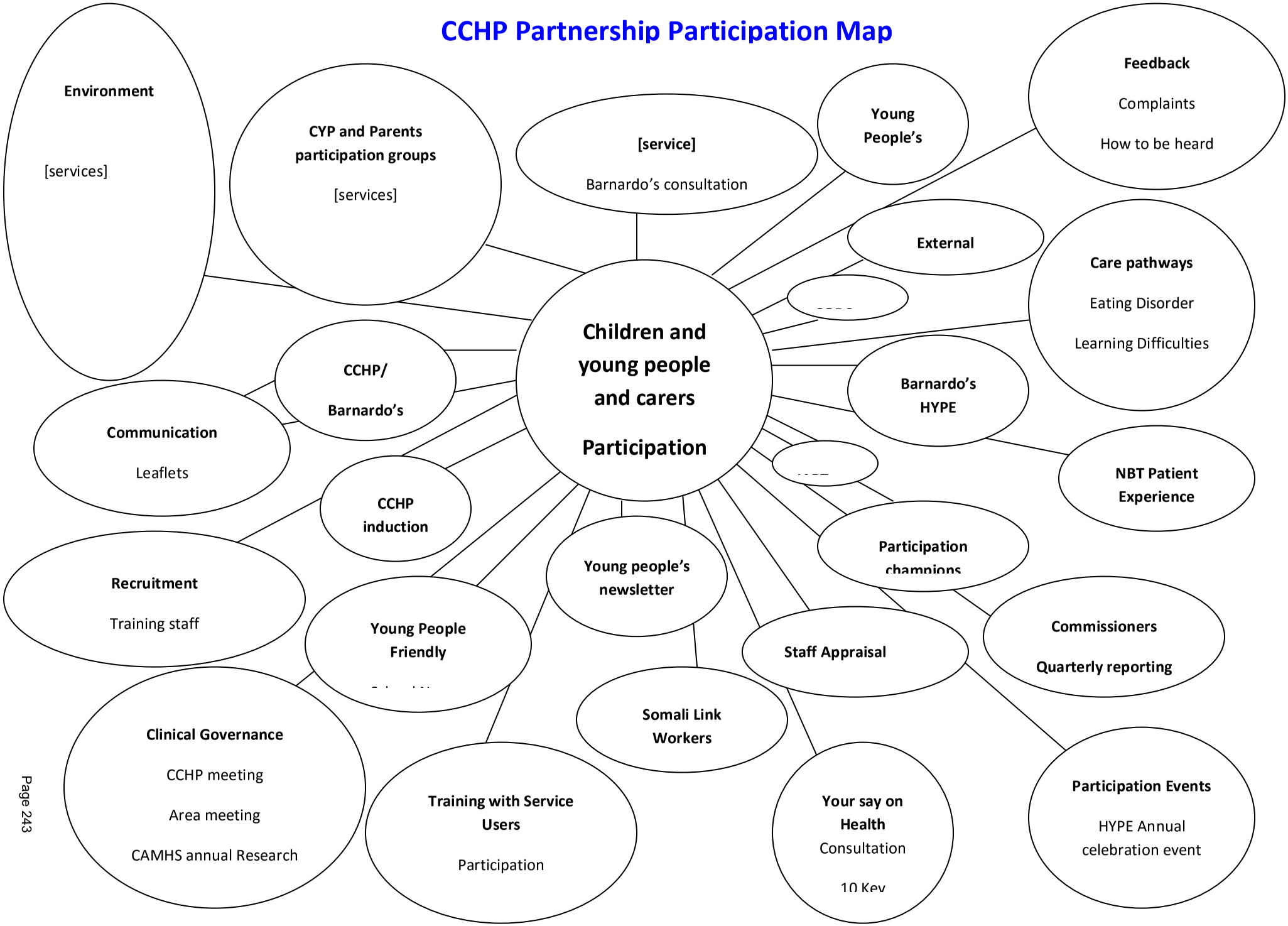
Actions:
Louca-Mai to feed back from parents and YP meetings at our next workshop, and invite YP to a final workshop in December.

Our next meeting will be at the same time and place [venue] on **Thursday 7th November**.

For the final meeting we hope to be joined by some of the young people involved. This meeting will be from 16.00-18.30 on **Thursday 5th December** (venue tbc).

[2] http://www.nya.org.uk/quality/hear-by-right
[3] https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services

CCHP Partnership Participation Map



CCHP STAFF PARTICIPATION WORKSHOP 2 - 7TH NOVEMBER 2013

Background

This document summarises the discussions on the second of a series of three workshops facilitated by Louca-Mai Brady, a researcher from the University of the West of England who is doing a project on 'embedding children and young people's participation in health and social care services'. She is working with CCHP to explore existing assumptions and practices around participation, and what is required for children and young people (CYP)'s participation to be embedded effectively. Further information on the background to the project is contained in the project information sheet and notes from the first workshop on 26/9/13.

Following on from the first workshop, this second meeting was structured around a **whole-systems approach to participation** (Social Care Institute of Excellence, Practice Guide 11, 2006[1]) and the four elements of culture, structure, practice and review which we are considering during these workshops.

UPDATE

Louca-Mai updated the group on the focus group she ran with parents on 23/10 and the first meeting of a group of young people involved in CCHP participation on the same day. One of the key issues to come out of the parents group was the issue of when and how parents and carers should be involved in participation – to support CYP's involvement and/or in their own right. The parents felt that their main role was to support the child's participation, especially when children were young, disabled or in need of additional support for some other reason (eg being very unwell). The group broadly agreed with this, but people also discussed how parents and carers shouldn't be seen as a proxy for CYP's views – ie parents and carers should be involved 'as well as' and not 'instead of' CYP.

A summary of the CYP's meeting is included in a separate document but the group looked at the flipcharts that were written in this meeting, in which the YP reflected on what 'participation' meant to them and what 'good' participation might look like. These flipcharts were referred to during various discussions during the workshop. The young people also suggested some ground rules for the workshop in December, which we agreed at the end of the meeting.

[1] http://www.scie.org.uk/publications/guides/guide11/

All actions from the last workshop had been completed, apart from the fact that some people had been unable to access the Google group. Despite these problems everyone said that they would like to use the group as a forum for sharing information and ideas and developing the strategy.

Actions:
Louca-Mai to check and resend instructions for joining the Google group
[participation manager] to liaise with Barnardo's IT dept to address problems with HYPE staff accessing Google sites
All to then join the group as soon as possible

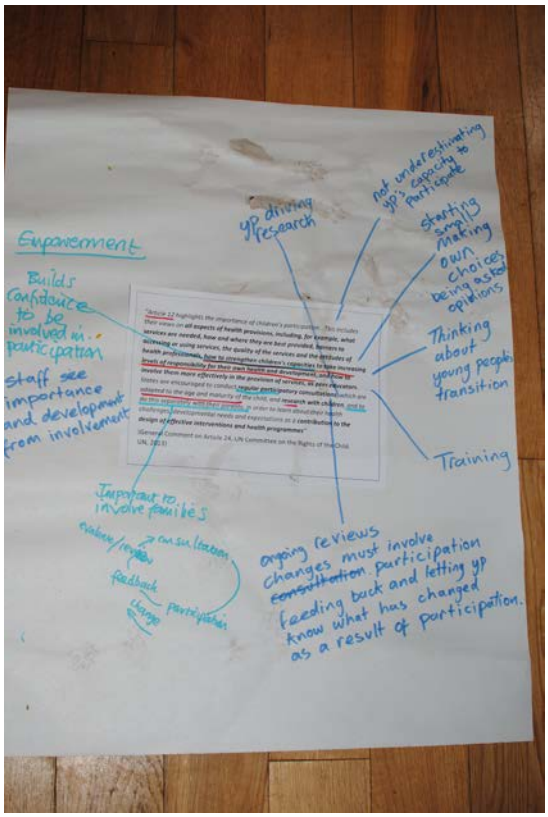
CHILDREN'S RIGHTS

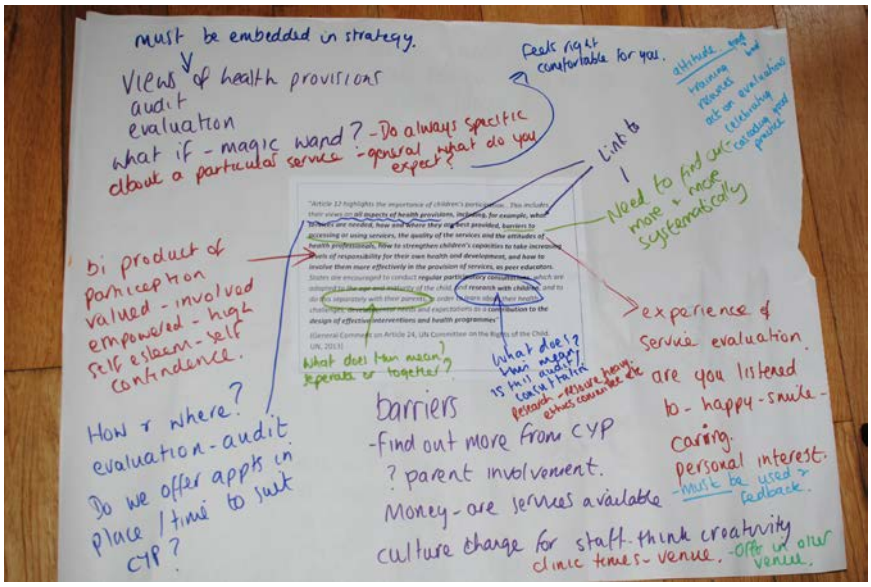
We started off by locating the strategy within the context of children's rights and the UN Convention on the Rights of the Child (UNCRC). (UNCRC: UN, 1989), which was ratified by the UK government in 1991. Article 12 of the UNCRC states that all CYP have a right to have a say in decisions that affect their lives and for their views to be given due weight in accordance with their age and maturity. This right is seen as central in enabling CYP to access other rights, including Article 13 (every CYP has the right to freedom of expression, including the right to all kinds of information and ideas) and Article 24 (CYP have the right to good quality health care and information to help them stay healthy) .

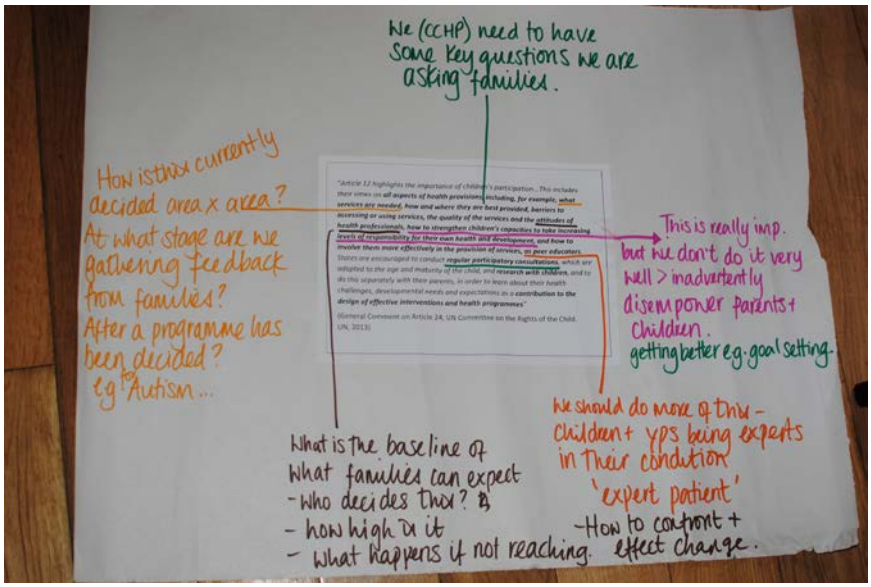
In small groups we considered the recent General Comment on Article 24 the UN Committee on the Rights of the Child, which emphasises 'the importance of approaching children's health from a child-rights perspective' (UN, 2013: 3):

"Article 12 highlights the importance of children's participation...This includes their views on ***all aspects of health provisions, including, for example, what services are needed, how and where they are best provided, barriers to accessing or using services, the quality of the services and the attitudes of health professionals, how to strengthen children's capacities to take increasing levels of responsibility for their own health and development, and how to involve them more effectively in the provision of services, as peer educators****. States are encouraged to conduct* ***regular participatory consultations****, which are adapted to the age and maturity of the child, and* ***research with children****, and to do this separately with their parents, in order to learn about their health challenges, developmental needs and expectations as a* ***contribution to the design of effective interventions and health programmes****"* (UN, 2013; 7).

In groups we considered this statement and its relevance to the embedding of participation in the CCHP, and added comments or ideas:







The UNCRC statement brought up lots of issues, and generated a really interesting discussion, which also links to the values underpinning our strategy (see 'culture' below). Key points emerging from the discussion:

- The need for <u>consistency</u> across CCHP was felt to be a key issue for the strategy and embedding participation. The strategy needs to set the culture and ethos for participation, and provide a baseline for what's expected of every CCHP service, and be relevant to all CCHP staff, so consistency and clarity are key but it needs to be balanced between being <u>ambitious and achievable</u>.

- Embedded participation in the CCHP is not consultation, but <u>meaningful involvement which gets reviewed, fed back and can be demonstrated to lead to change</u>

- Feedback: both getting feedback from CYP and families (CYPFs) using, or potentially using, CCHP services and feeding back to CYPFs on what has changed as a result of their participation

- The CCHP needs to be robust enough (at organisational, area, service and individual levels) to hear and respond to what CYPFs say without being defensive

- Going beyond feedback: asking CYPFs (including those not yet accessing CCHP services) what they need or would like beyond or instead of existing services

- Inclusive practice: key value is that all CYP can participate. So we shouldn't underestimate CYP's capacity to be involved, but instead start from where they are and build up (for eg using creative/flexible methods and integrating participation into everyday care for some CYP)

- Communicate clearly to all CYPFs using CCHP what their rights are: design a leaflet about children's rights and participation opportunities which is given to all CYPFs accessing CCHP services and available at all services

- Using goal-setting and other tools consistently across CCHP, especially during transition

- Participation/UNCRC as a tool to empower CYP to take control and make informed choices in relation to their own health and care. This could also be linked to person-centred planning

PRACTICE

We then looked at again at the various participation tools and models people had agreed to consider after the last workshop, which were stuck on the walls around the room. These included Hear by Right[2], Young People Friendly[3] and others saved in the Google docs folder. We discussed whether and how are these were useful and relevant (or not) to embedding CYP's participation in the CCHP. People felt that the CCHP participation framework was the most helpful, and could be adapted to help people implement the strategy in their service/project. The framework will be linked to the values and principles set out in the strategy (see 'culture' below), as well as to the UNCRC, Young People Friendly and other relevant models, tools and resources.

[2] http://www.nya.org.uk/quality/hear-by-right

[3] https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services

Actions: [participation manager] and HYPE team to look at the framework and consult with the sub-group who have expressed an interest in working on this and values before the next workshop.

STRUCTURE

Thinking back to the work we did last time on the infrastructure required to embed CYP's participation in the CCHP, we looked at the revised map that [participation manager] had drafted following our discussions last time. This was translated into a large map on the floor and people identified what they thought were:

- Enablers (what will make it happen?)
- Barriers or areas needing attention (what could stop it happening or slow it down?)
- Gaps (is there anything missing that needs to be there for participation to become embedded?)

Action: [participation manager] to write up and consider the discussions on structure with Louca-Mai and the project core group

CULTURE

For the final part of the workshop we briefly returned to our starting point for these workshops – the values which will underpin the strategy. Louca-Mai suggested the following definitions, which we agreed to try and work with:

- Values: overarching ideals
- Principles: statements which describe the values in more detail, providing further information and context
- Standards: operationalization of principles – giving a clear idea of what will happen, and how it will be assessed

Actions:
All to think about values, principles and standards they think are important and share any thoughts and ideas via the Google group
[participation manager] to lead on developing draft values in consultation with a sub-group from the workshop we have expressed an interest and via the Google group
Louca-Mai to plan session on values, principles and standards at December workshop with YP

THE STRATEGY

Through our discussions about what the strategy might look like and contain the following parameters were agreed:

- The strategy will be 1-2 pages long and set out the values and principles for CYP's participation in the CCHP, with an acknowledgement of the role parents and carers play in facilitating this
- There will be no more than six values in total (eg 3 to a page with related principles) and these will be written in plain English so they are understandable to CYPFs
- These values and principles will be linked to standards and related key indicators set out in the CCHP participation framework (revised if necessary to be in line with the values and standards)

- The strategy needs to set the culture and ethos for participation, and provide a baseline for what's expected of every CCHP service
- It needs to be relevant to all CCHP staff, so consistency and clarity are key but it needs to be balanced between being ambitious and achievable
- The strategy and framework will draw on and signpost people to existing tools and resources
- Linked to the strategy will be leaflet about children's rights and participation opportunities. This will be co-designed with young people and given to all CYPFs accessing CCHP services and available at all services

Process

- A draft strategy will be developed and discussed at the workshop in December (see below) and then finalised
- Once it is signed off and disseminated, services/parts of CCHP will be expected to develop a participation plan using the framework and strategy, and report back on this.
- The strategy will be rolled out through team, area and management meetings, with the development and implementation of participation plans piloted in a few services (ie Louca-Mai will work with a service/services to do this first as part of the next action research cycle for this project)

Next meeting

For the final meeting in this cycle we will be joined by some of the young people involved in the project.

This meeting will be from 16.00-18.30 on **Thursday 5th December** at [venue]

Children and young people's participation in the CCHP

About the project

- Louca-Mai Brady, from the University of the West of England, is working with young people and staff from North Bristol NHS Trust (**NBT**) and Barnardo's HYPE project to look at how children and young people can best be involved in the Community Children's Health Partnership (**CCHP**).
- If you want more information have a look at the information sheet or other newsletters you should have been given. If you haven't seen this then let Louca-Mai or a member of the HYPE team know.

What has happened so far?

- There have been two workshops (meetings) with CCHP staff, one with young people, and two (December 2013 and February 2014) where we all came together.
- At the December meeting, which we'd planned to be the last one, people said that they thought we needed more time and would like another, longer workshop to agree what the final strategy should look like. We agreed to do this in the February half term as that made it easier for young people to be there. This newsletter is about that February meeting.

Our meeting

At the meeting we started off by with some 'Smartie speed-dating' to get to know each other a bit more (and eat some chocolate!) and then talked about:

- What we'd all done so far in earlier meetings
- A recent clinical governance event that [Participation manager] and some other group members went too (Louca-Mai was stuck in London because of the floods!), where they talked to lots of CCHP staff and managers about the work we're doing
- Looked at posters of all the work we've already done and talked about what we thought was most important
- Did lots of great creative stuff designing posters and T-shirts promoting the strategy
- What will happen next

More information on all of this is in the newsletter, but first here's **a young person's report on the day** by [young person]

Personally this was my favourite meeting so far. The fact that was half term meant that we had the opportunity to meet for a full day- giving us more time to get to know each other, discuss the strategy and put forward our ideas in a more creative way. It was relaxed and loosely structured so that the day could follow a natural direction, which I think worked really well.

By the end of the session we had made a story board, t-shirt and poster designed to promote the strategy. Each was produced by a mixed team of CCHP staff and YP and it was really interesting to come together and see what each other had come up with. Everyone seemed to be really absorbed in the creative activities, especially the staff for whom I think it was somewhat of a novelty!

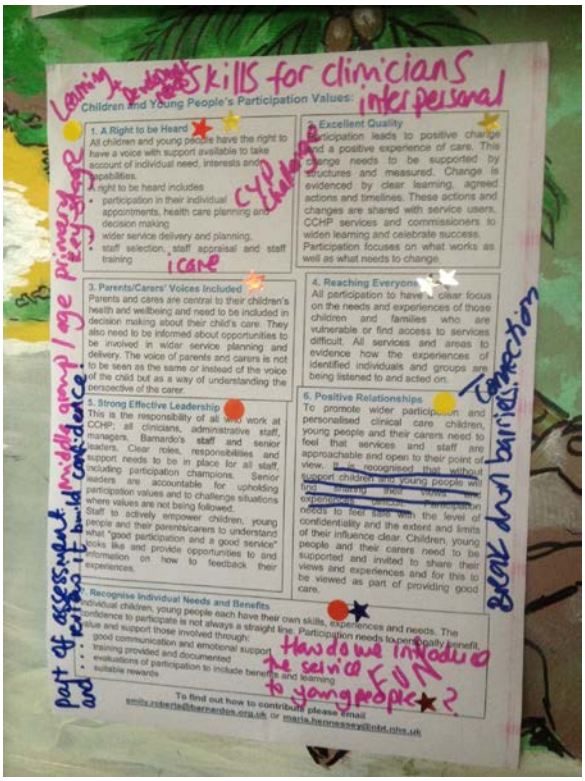
I can only speak for the group or team I was in, but this partnership seemed to ignite a lot of enthusiasm and discussion, far more than previous meetings. I think that having this practical aspect to our meeting really broke down barriers between staff and YP and I am in no doubt that the end result wouldn't have been nearly as good if the adults and YP had worked in separate teams. The power of creativity cannot be underestimated and I think it really facilitated expression and cohesion. By the end of the day I really felt as though we were an equal group and that there was no disparity between YP and staff.

I am struggling to remember exactly what was said as due to my disorganisation I am writing this a week later without any notes! But the one thing that is really poignant in my memory is the word collaboration. I left feeling really hopeful that this collaboration was definitely the way forward and the thing that was going to make this strategy authentic and meaningful and more than words on paper.

To my mind the next things we need to think about is how the strategy translates to young people, how we can make it mean something for them. How do we communicate to YP what they can expect from good health care and what 'good' looks like in practice?

The morning (Louca-Mai)

We started off by looking at some of the things we'd done in earlier meetings, and making notes on them about the things we thought were most important:



After that we talked in pairs or threes and came up with some '**how do we…'** questions that we thought the strategy and framework needed to answer to help us embed participation in the CCHP:

HOW DO WE … let young people know about their rights/ how to feedback who can they talk to?

…. know/ make sure we are hearing, and responding to the views of ALL ages of children?

… make sure information is accessible to everyone, including disabled children, including using technology to do this?

…make sure that young people's rights and the way staff deliver a service give young people the opportunities to be empowered/ fully involved in their health care?

… know when children are able to make decisions about their medical care, and what preparation and support they need to do this?

… describe what young people can expect?

… make sure children and young people have a named worker and are able to ask for a different worker if they want too?

… reach children and young people who are hard to reach as a result of circumstances beyond their control?

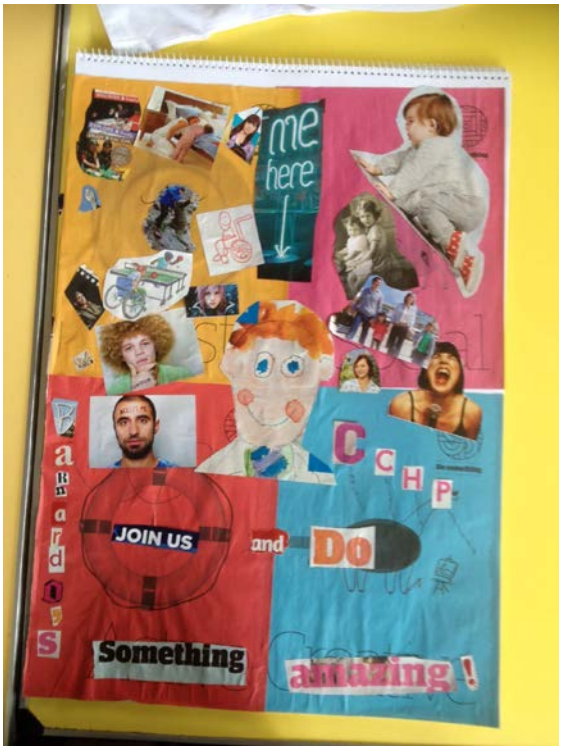
… motivate reluctant staff and make participation sustainable, real and part of people's everyday work

All the information from these exercises will be used to write the next draft of the strategy, and we'll send this to everyone in the group when this is finished. If you want more information on what people said let Louca-Mai know and she can send you the write up of the flipcharts.

The afternoon ([participation workers])

After lunch and a 'would you rather….' icebreaker, we started to look at ways of promoting the strategy to both staff and children and young people. First we looked at 'Strategy Words' pulled from the document, laid out on the tables in the room. We asked everyone to pick two words that felt important to them getting into pairs to talk about why we chose the words/phrases and how we could use these in promotional materials.

Next we broke into two groups. Group 1 worked on putting the strategy into a poster form using lots of pictures and words from magazines. As part of this they were asked to come up with a strap line outlining the message they wanted to get across. In this case it was 'Join Us and Do Something Amazing'.



Group 2 were asked to design a t-shirt to promote the strategy using stencils, text and free hand painting. The t-shirt had the key message ‘Everyone’s Responsibility’. The group also created a photo storyboard using words selected at the start of the afternoon and again images from magazines. The message in the centre of the storyboard was ‘Life feels better when you have a plan’.

At the end of exercises we all fed back to the group and discussed how we would like young people to take elements of all these ideas to a designer and begin developing final promotional materials for the strategy.

At the end we all wrote down **one thing we were taking away from the day**:

- I have learnt more about the NHS.
- To share how you feel with people you work with. Working in teams is challenging, but fun too.
- Great ideas from everyone.
- Working with CCHP and YP
- I can ask for another worker and tell them how I feel.
- The buzz …
- Fun
- Positivity and partnership are effective tools for change.
- How great and effective joined-up working is.
- Fun, interactive session. Good to create (with Tom!).
- Working in groups can be a challenge but it is worth it.

… and **one thing we thought needed to happen**

- Keep up joint meetings, YP/ CCHP/ Barnardo's.
- Advertise and promote the strategy, T-shirts
- Mandatory training for all staff, with young people presenting and management involved
- How we can use 'Loud Mouth' in rest of CCHP.
- Involve more staff as soon as possible
- Learning and development across CCHP
- To really think about how to reach children and young people.

Then [Participation manager] asked everyone to make a pledge for **NHS Change Day** and here's what people wrote:

- LD Nurse Team:
  - Change our initial assessment meeting with families – clearer information.
  - Make a DVD showing the path through our service. More feedback from individual children sessions and family sessions (simple feedback forms).

- I will embed participation in the family nurse partnership from the start.
- My pledge is to speak my mind.
- Develop my new role as participation champion
- Devise and document ways to evidence impact of participation.
- Go to all my appointments and get there early so I am not late.
- To obtain BME YP views re: participation for EC work.
- Embed participation in school nursing.
- To consistently and continuously raise participation awareness
- Use technology/ film in participation work.
- - To encourage the BME groups to be involved in participation.
- To give children and young people the name and contact details of someone if they need to change their worker.

What will happen next?

- [Participation manager] will make changes to the strategy and framework based on the things we discussed at the meeting
- Some of the HYPE staff young people work with young people to design the materials, and write a cover letter to go with the strategy, which Louca-Mai will then test out with other groups of young people
- The HYPE team will also talk to young people who've been involved in the project about what they think about it so far, and how they'd like to be involved in the next stages
- Louca-Mai and [Participation manager] will also talk to CCHP managers and CCHP staff, parents and other people who are interested, to get their views on the strategy
- This workshop is the end of the series of meetings we planned to develop a CCHP strategy, and so the next step is for Louca-Mai and [Participation manager] to put these ideas into practice, and work with a CCHP service to see how we can use the strategy and framework to 'embed' children and young people's participation in CCHP services
- We'll be looking at things like how young people can be involved in training and other things CCHP do to make the strategy happen, and also how we will know what works and what doesn't (monitoring)
- We also talked about how we let people know about the strategy – both people who work in CCHP services, and other people who work with them; and children, young people and families who are (or might be) using CCHP services. We also talked about the need to let people know about this work more widely. Ideas suggested included:
  - Slot on 'Friday Five'/ bulletin info participation newsletter
  - Publicity/ event at end of project . Communications, internal: intranet and facebook
- In the meantime we'll write more newsletters to keep you updated on what's happening. There will also be meetings in the Autumn, for people who are interested, where we'll look at what we've learnt from doing this project.

Thanks again for all your commitment and hard work and please keep in touch:

You can contact Louca-Mai by email: louca.brady@uwe.ac.uk or by phone/text:

What is Participation?

Participation is a process and culture in which children and young people are listened to, their opinions respected and they are actively involved in decision making which brings about change in themselves, their peers, the services they use and their communities.

We need input from all levels of the organisation and we invite everyone to contribute to make this a success.

Please contact xx or xx for more information.

Believe in children Barnardos

In partnership with:

Community Children's Health Partnership

North Bristol NHS Trust

CCHP's Children & Young People's Participation Strategy

"Participation is not a straight journey, it twists and turns and can take several tries before you get where you want to be. It's not a physical thing; it's an attitude, a cultural mindset.

Good participation can help bring good out of a bad situation and break the isolation."

2014 - 2017

Background

CCHP exists to provide excellent quality health care for all children & young people in Bristol and South Gloucestershire. To achieve excellent quality, CCHP value two equally important clinical governance principles:

- The need for competent staff, using best evidence in the care they offer
- To work in a compassionate and participative way to provide the best experience possible

Children, young people and parents/ carers can find accessing health services daunting. A commitment to participation, values people as individuals.

The CCHP with Barnardo's is about strengthening the collaboration between staff, services & children, young people, parents, carers through participation. Working together for real and positive change. Participation is central to our ethos to improve health and well-being. This includes Equalities and Diversity and Safeguarding.

The Department of Health and NHS England have shown an increasing commitment to participation; including The Health and Social Care Act (2012), NHS Outcomes Framework (2014/15), NHS Constitution (2013), and improved Access to Psychological Therapies (IAPT).

Making children and young people's participation a reality is a duty stated in the UN Convension on the Rights of the child (UNCRC, 1989). The UN committee on the Rights of the Child recently emphasised 'the importance of approaching children's health from a children's rights view point' (UN,2013:3), to include:

- What services are needed
- How and where they are best provided
- Barriers to accessing or using services
- The quality of the services
- Attitudes of health professionals
- Strengthening children's capacities for increased responsibility in their own health
- Involving service users more effectively as peer educators

This participation strategy was developed by a group of young people, CCHP and Barnardo's staff and is part of the North Bristol Trust's Patient Experience strategy. It has been supported by Louca-Mai Brady from the University of the West of England, with contributions from parents, clinical leaders, managers and commissioners through a series of focus group discussions.

Our ambition is to establish participation as an everyday process - understood, valued and acted upon by professionals and children, young people and their parents/carers. The CCHP self-assessment framework of participation standards means that services and functions can apply this strategy to the work they do.

Our Participation Values

Children's Right to be Heard

Participate in decisions about their health care & influence the services they receive.

Children and young people using CCHP services will experience:

- Responsive staff who understand the importance of listening to children
- Frequent opportunity to give feedback & make choices
- Clear information that meets differing needs

Parent's Right to be Heard

Included in decision making about their child's health care & the services they receive.

Parents often have an important role in supporting their child's participation. However, the views of the parents & carers should be included as well as, not instead of the children's views.

Differences of view always need to be seens in terms of the best interests of the child.

Reaching and Supporting Everyone

Especially those most in need and least heard. Participation can engage and benefit all children, young people and families through:

- Being genuinely interested in the person
- Working and learning together
- Good communication and planning
- Seeing the difference it makes
- Social opportunities to make friends
- Developing knowledge, skills & confidence
- Valuing their contribution
- Celebrating success
- Using the creative arts and technology
- Making it enjoyable and FUN!

Respectful Relationships

Participation is about people and relationships that support engagement. Good communication skills matter. All staff should communicate in a way that encourages listening and understanding to:

- Develop trust
- Manage different points of view & difficult conversations
- Improve decision making

Excellent Quality

We will ensure our quality through:

- Using national standards
- Monitoring progress
- Clear participation structure
- Action planning
- Identifying the positive changes that result

Strong Effective Leadership

CCHP managers, professional leads & supervisors have a responsibility to lead and actively promote good participation through:

- Developing high quality services
- Upholding participation values and practice
- Supporting & developing staff
- Sharing good practice, locally and nationally
- Enabling positive change

The Self Assessment Framework 2014 - 2016 for Children and Young People's Participation

Community Children's Health Partnership (CCHP) with Barnardo's

Community Children's Health Partnership

Believe in children Barnardos

HYPE

Helping Young People (children and families) Engage

HYPE
Helping Young People (children and families) Engage

Introduction

This framework sits alongside the Community Children's Health Partnership's Children and Young People's Participation Strategy. The strategy outlines 6 key values to support participation and summarises the local and national context for participation. In order to create lasting change through embedding children and young people's participation in all aspects of service design and delivery, we have adopted the Social Care Institute for Excellence (SCIE) 'whole-systems' approach to participation based around 4 elements:

Culture

The ethos of an organisation, shared by all staff and service users which demonstrates a commitment to participation.

Practice

The ways of working, methods for involvement skills and knowledge which enable children and young

Structure

The planning, developing and resourcing of participation evident in organisation's infrastructures.

Review

The monitoring and evaluation systems, which enable an organisation to evidence affected by participation.

How the Framework Works

This framework is a development tool to apply the principles of the linked participation strategy and the UN Convention on the Rights of the Child to the whole CCHP organisation and all its services. It is designed to help identify priorities as well as an on-going demonstration of progress towards embedding children and young people's participation. As partners in the CCHP, Barnardo's aims to improve participation, with a particular focus on vulnerable and disadvantaged children. This involves supporting services to assess levels of participation; to identify improvements and developments.

Completing the Workbook

We have developed this framework alongside services so that it is as readable and relevant as possible. We anticipate that each time a service goes through this process new insights will be developed and we will take these into account when we review the framework in 2016.

While this is a self-assessment Barnardo's will be available for support and guidance throughout the process.

- The workbook is completed and then reviewed annually by services
- The process needs to include managers, front-line staff and reception staff and be informed by the views of children and young people
- Each standard should be scored and evidence given for the score

The scores to consider are:

1 Not in place; 2 Currently being developed; 3 In place, but needs improving; 4 In place and effective; 5 Established/embedded

- Actions should be given priority where scores of 3 or less have been given.
- The workbook should then be used to create an annual service action plan that is S.M.A.R.T. (Specific, Measurable, Achievable, Realistic and Time-bound.)

The Barnardo's (HYPE) service is available to support this process including the on-going action plan.

HYPE
Helping Young People (children and families) Engage

1. The Culture

There are values of Welcome; Listening; Choice

1	**Recruitment** Children, young people, parents and carers are actively involved in the recruitment and selection of all staff. Service users are supported in their involvement.	**Initial Assessment:** **Evidence:** **Action Plan:**
2	**Induction** Staff attend participation training. CCHP values; the pledge and mission are discussed with all new staff.	**Initial Assessment:** **Evidence:** **Action Plan:**
3	**Teams** Teams and services have at least one event a years to reflect on their participation practice. Teams regularly discuss participation and inclusion in team meetings, share practice and develop a learning culture. Teams contribute to clinical governance and share learning across the partnership.	**Initial Assessment:** **Evidence:** **Action Plan:**

4	**Ongoing CPD** Staff have opportunities for ongoing CPD around children and younf people's participation. Staff reflect on the impact of participation in their annual appraisal. Staff attend iCare training.	**Initial Assessment:** **Evidence:** **Action Plan:**
5	**Inclusion** Teams monitor take up by disadvantaged groups and least heard groups including BME. Services understand the experience of these service users and develop their service to meet their needs.	**Initial Assessment:** **Evidence:** **Action Plan:**
6	**Networks** Partnerships and links are made with other groups and organisations, especially those that represent children, young people and parents.	**Initial Assessment:** **Evidence:** **Action Plan:**

Appendix 8: CCHP report for NHS Expo

Embedding Children and Young People's Participation in Health Services

August 2015

Research Summary

Louca-Mai Brady

Postgraduate Researcher, University of the West of England

xx

Barnardo's Participation Manager

Acknowledgements

The authors of this report would like to acknowledge the 38 CCHP staff from North Bristol NHS Trust and Barnardo's, and the 15 young people who together were involved in the collaborative workshops, meetings and related work during this project. Without their contributions and commitment this project would never have happened. These include, but are not limited to: <names deleted>.Thanks also to the parents, commissioners and others who participated in focus groups and other discussions.

Also grateful thanks to North Bristol NHS Trust, Barnardo's and the University of the West of England for their support of this project.

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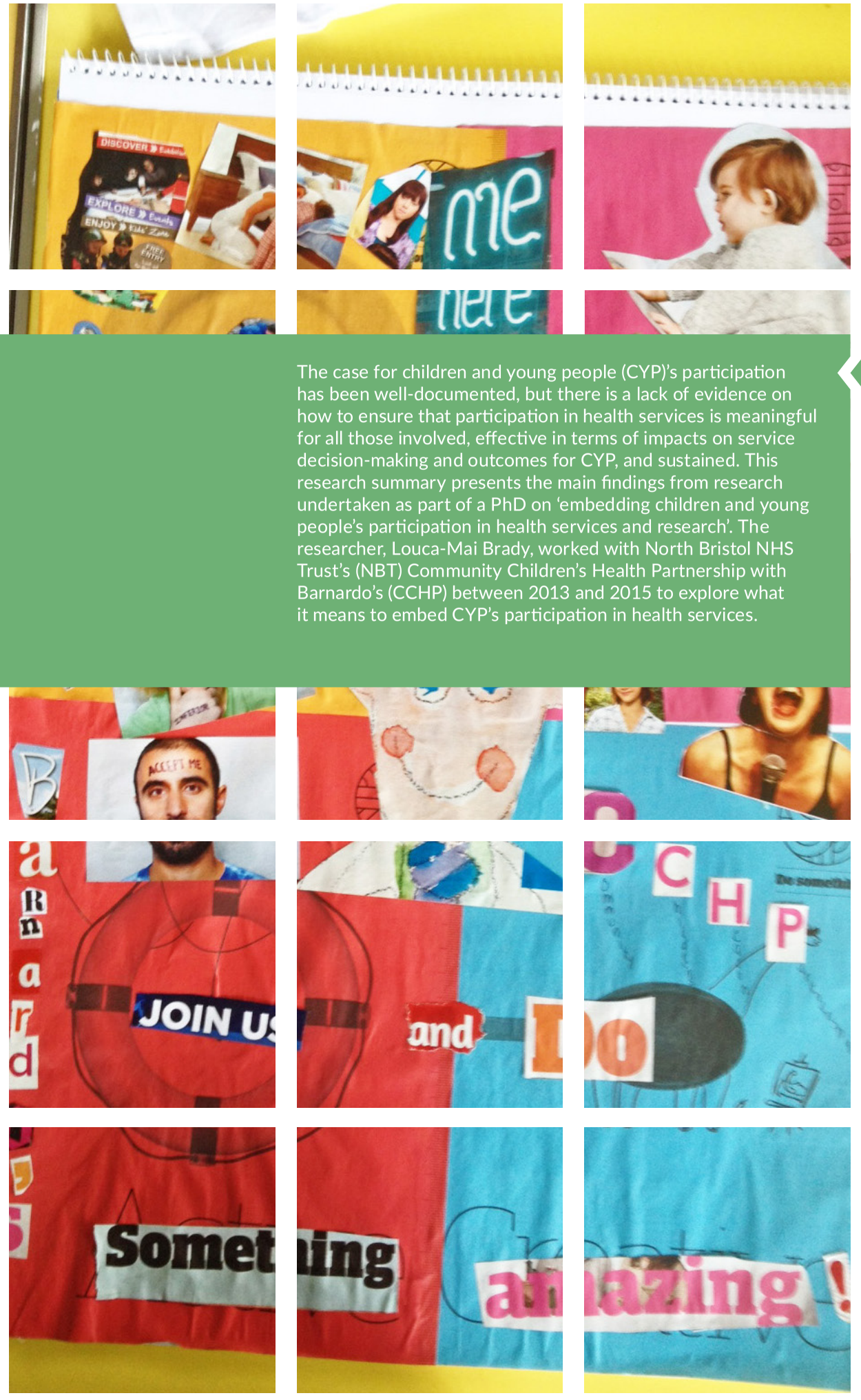
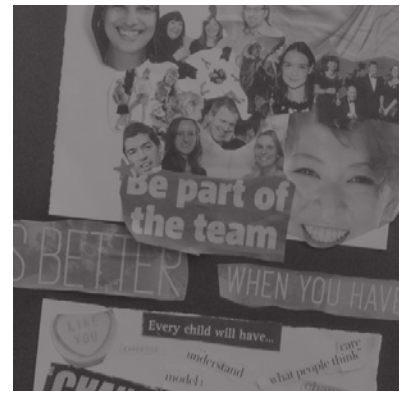
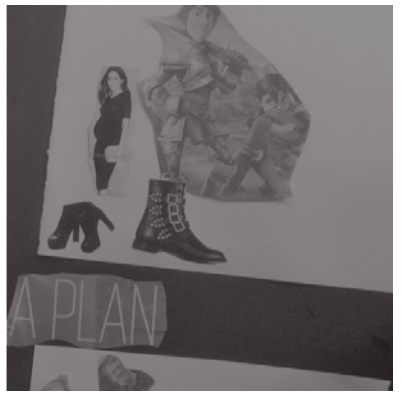


The case for children and young people (CYP)'s participation has been well-documented, but there is a lack of evidence on how to ensure that participation in health services is meaningful for all those involved, effective in terms of impacts on service decision-making and outcomes for CYP, and sustained. This research summary presents the main findings from research undertaken as part of a PhD on 'embedding children and young people's participation in health services and research'. The researcher, Louca-Mai Brady, worked with North Bristol NHS Trust's (NBT) Community Children's Health Partnership with Barnardo's (CCHP) between 2013 and 2015 to explore what it means to embed CYP's participation in health services.





Summary

Understanding participation. In order for participation to be embedded there needs to be a shared understanding of what participation means, both individually for CYP as users of health services and collectively in service design, delivery and evaluation.

A shared commitment. Embedded participation needs to be seen as a priority, underpinned by a shared vision and values which are clearly articulated in a strategy, but flexible and adaptable enough to be relevant to all services and service users.

Participation needs to be part of the culture, structure, practice and review processes of health organisations, a 'whole systems approach' (Wright et al., 2006) with CYP's rights at the heart. Embedded participation needs to happen, and be prioritised:

» At all stages, from service design and commissioning to delivery and evaluation

» At all levels, with people to champion participation at service, area, and management levels as well as CYP being involved wherever possible

» In all aspects of work including day-to-day delivery of services, team and management meetings, staff recruitment and appraisal, training and in organisational policy

» For all CYP. All CYP who are current or potential service users should be informed of their right to have a say about the services they use, the organisation's commitment to participation and opportunities to get involved. Participation opportunities and activities should ideally be developed in collaboration with CYP, and seek to be as inclusive, accessible and relevant to CYP's lives as possible.

Background

Participation it is commonly defined as a process by which individuals influence decisions which bring about change in themselves, their peers, the services they use and their communities (Kirby et al, 2003; Participation Works, 2010). The case for CYP's participation has been well-documented but the various theories and models of CYP's participation are often not clearly linked to the wide range of models, toolkits and 'how to' guides which are available (Malone and Hartung, 2010). There is also little existing evidence on how the available tools, guidance and criteria actually support the embedding of CYP's participation in health and other services.

CYP's rights both in relation to decisions about their own health care and concerning the development of services are underpinned by the United Nations Convention on the Rights of the Child (CRC: UN, 1989), ratified by the UK government in 1991. A key implication of the CRC is the understanding that all children have needs that must be met in order to optimise their health and wellbeing, and the CRC establishes international recognition that all CYP have a right to the highest possible standards of both healthcare and participation (Alderson, 2014), something which is increasingly reflected in law, guidance, regulation and policy in relation to health and more widely (Franklin and Sloper, 2005). But, although CYP's participation in health services is becoming more common, and has an increasing profile at a national level (for example through the NHS England Youth Forum) many CYP are still not involved in decisions about their own health care or about the health services in their local area, and that there are considerable variations both regionally and in the age and background of those who participate (CRAE, 2015). Austerity measures have also reduced the range of services that protect and fulfil children's rights in health and related areas (OCC, 2015).

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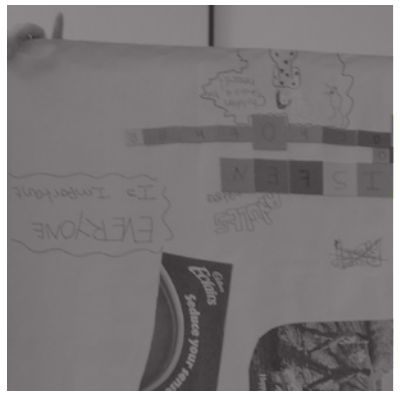
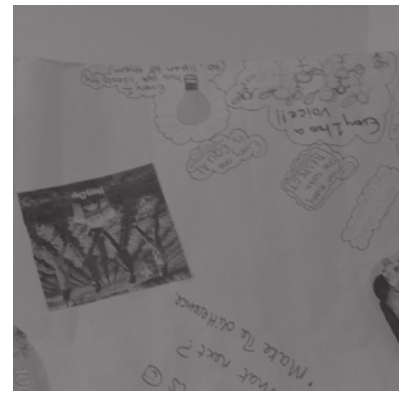
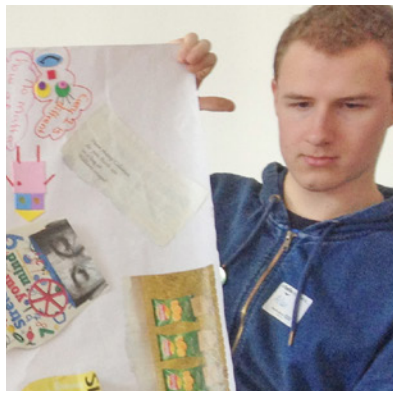
Methodology

The project involved a two-stage, participative process in which Louca-Mai facilitated a series of collaborative, action research-based workshops with CCHP managers and staff from both North Bristol Trust and Barnardo's and young people who had been users of CCHP services. Other groups including parents, commissioners and CCHP management and clinical leader groups were consulted through a series of focus groups. The first stage focused on the development of a strategy and framework to underpin the embedding of participation, and in the second stage a CCHP team (the Community Paediatric Physiotherapy service) were supported to put the strategy and framework developed in stage one into practice, and look at what it meant to 'embed' CYP's participation in their services.

Alongside this work the young people involved in the first stage decided that they wanted to develop material for young people about the strategy ('*Our Mission*') and CCHP's participation work, so were supported to do so by Barnardo's staff. This resulted in the film *'What goes on in there?'* which can be viewed at:

http://www.nbt.nhs.uk/cchp/visiting-cchp/what-goes-there

Key Findings

Understanding Participation

» Children and young people's participation involves both individual and collective participation and the connection between the two:

"People needed to be empowered and feel empowered, both the children and family, whether that is in their day to day care...or acquiring knowledge and experience and skills to take place in other forms of decision-making within services".

» CYP need to be at the centre both in terms of principles and vision (e.g. the strategy) and in practice, based on a commitment to children's rights:

"I like how [the strategy is] underpinned by the UN convention, it's in the core values, you can't ignore it. It's not optional, it's like, we're going to do this, so how do you want to do it?"

"[It's] about people being really genuinely interested in you as a person as well as your views about participation, because I feel like I couldn't really trust that somebody was really interested in my views about a service if I didn't feel like they were interested in me as a person" (young person (YP)).

» Participation needs to be a meaningful process for all involved, both services and CYP:

"It needs to be meaningful...feeling as though you are actually making a difference and people aren't just listening to you so that they can tell their boss that they've listened to a young person" (YP)

"[I got] involved in participation work [because]...I wanted to be able to use my experiences to help change services a little bit and to make them better" (YP).

» Participation should be part of the culture of the organisation and seen as everyone's responsibility:

"[Participation is] a collaborative effort... everybody's job...not just the responsibility of one particular person or one particular service...we all should be doing it"

But at the same time it was recognised that participation also needs expertise, leadership and people to champion it, if not formal 'champions'.

Key Findings

Participation in Practice

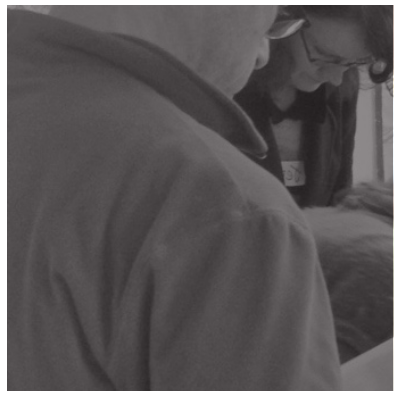
» It is important to understand the particular challenges of NHS organisations and service users:

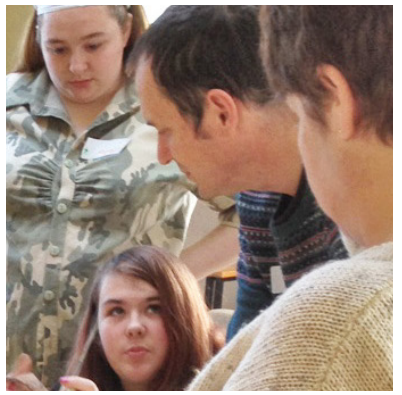
"Particularly when you're talking about [participation in] health as well...children who are ill... I think there are various kind of considerations"

"If the young person doesn't like that clinician, doesn't feel that clinician is listening, how can we actually tell young people that they can get their clinician changed? Because actually that's the right thing to do"

» The range of services within NHS organisations like CCHP means that it can be difficult to map and monitor participation practice and develop a shared vision which is relevant to all services. This requires a process which, while promoting shared vision and values, is also flexible and adaptable to the diverse needs of different CYP, families, and services:

"We know that we do [participation] but we need to demonstrate that we do it and we need to find a way of making sure that everybody does it in a similar way"





Key Findings

Participation in Practice

Continued

"Each service or discipline... [needs to have] their own specific plan coming from the strategy. So, the idea is that you create an ownership through that...because the partnership is so diverse, it's how you term that in a way that feels like you're backing up the need for consistency"

» It is important both to recognise CYP's expertise and also the need to sometimes build capacity to participate, particularly for those who are less likely to be involved:

"We might think that young people might not be in the right place or aren't ready to participate...when actually those might be the times that...they really need to and enable them to take some responsibility about their health"

"[It's about] recognising that [some children and young] people needed support to be included, that this couldn't happen by itself and people needed to be empowered and feel empowered... so it is about building people's capacity to be included"

» CYP should of course have opportunities to have a say about their experience as patients or service users, although recognising that even this can sometimes be challenging:

"We need to recognise that [some] children and young people are going to find it hard to give their feedback, especially if it's not positive ... the more they feel like you're serious about what they think the more they're likely to trust you and actually say it"

» CYP should also have a say in how they think existing services could be improved and through involvement in staff recruitment and training. But the project found that embedded participation in health services needed to move beyond situations in which adults are setting the agenda, and seek to provide more opportunities for CYP to have an active and ongoing role in shaping how health services, projects and programmes are commissioned, designed and delivered as well as being involved in evaluating those services:

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"What we generally don't do is [say]...' if we had a magic wand and we could provide you with a health service, what would you want it to be?' So, we ask them what they think of something what we've already come up with the idea for, but we don't necessarily ask them for the idea"

"Children can...describe a utopian health service. Obviously you won't be able to provide that, well, you might...but it's how you manage that discussion... you wouldn't [want to] disappoint them"

"it's a kind of cultural, behavioural shift isn't it? ... [For staff to be] okay about receiving those comments [from CYP and families] and not feeling threatened by them".

CCHP and Barnardos are finalising their actions from the full report findings and have started implementing the strategy and assessment framework across services. To find out more, the full research report, young people's video and other information on CCHP's participation work are available at:

http://www.nbt.nhs.uk/cchp/what-cchp/young-peoples-participation

Further information on Louca-Mai's research is available at:

www.younghealthparticipation.com

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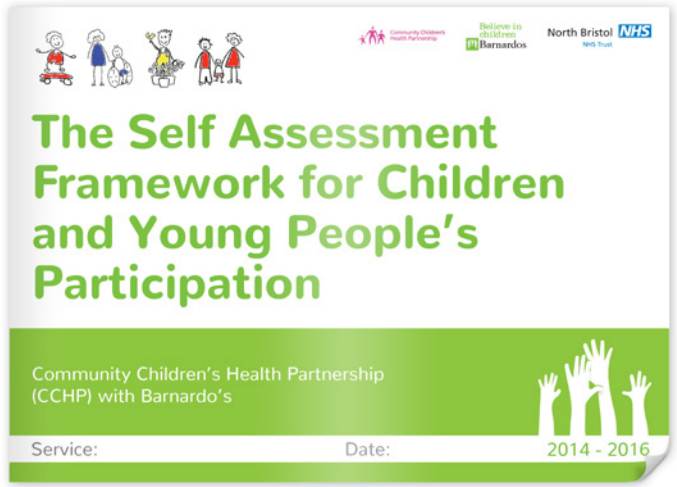
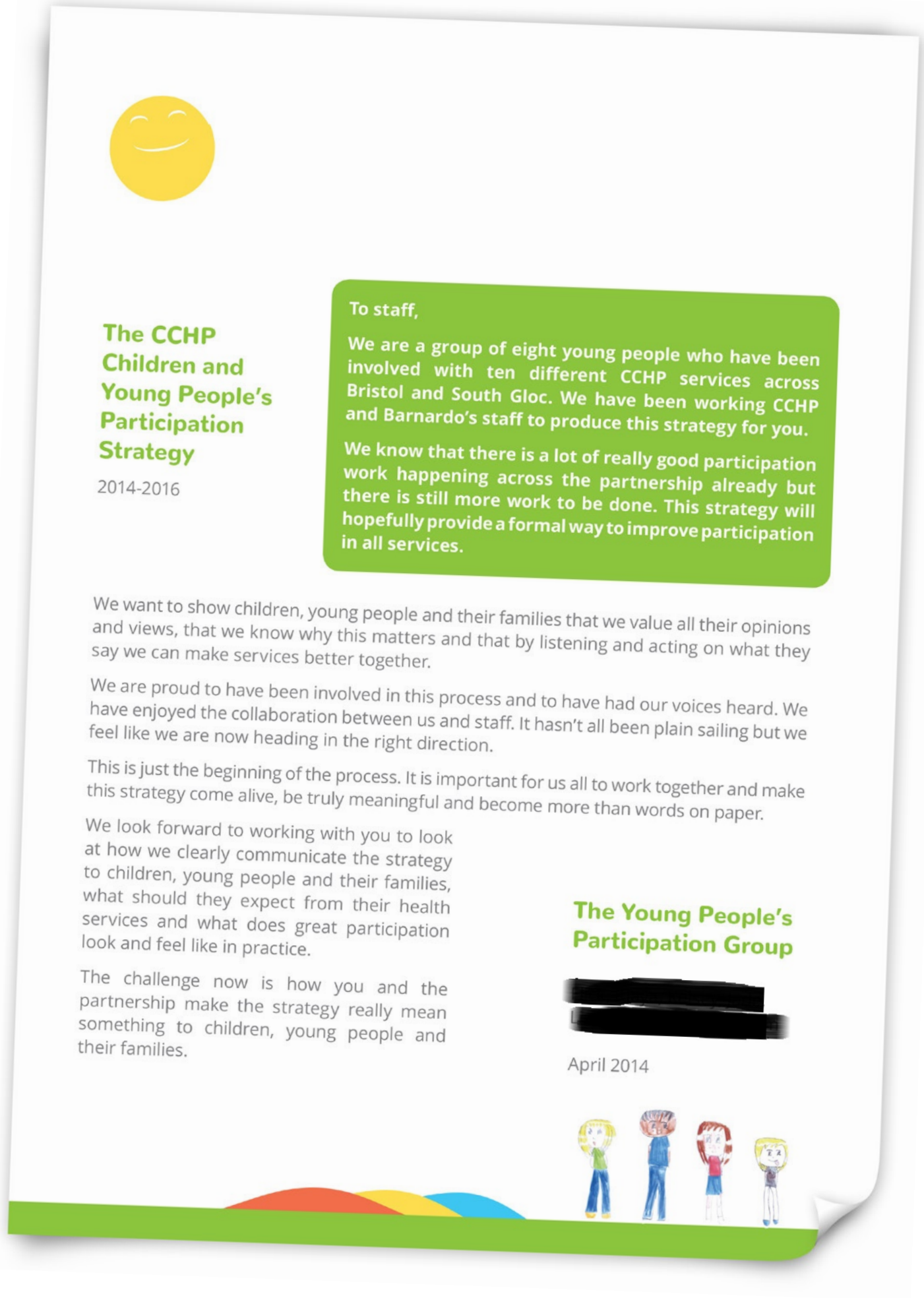
Appendices

Below: Front cover of The Self Assessment Framework for Children and Young People's Participation

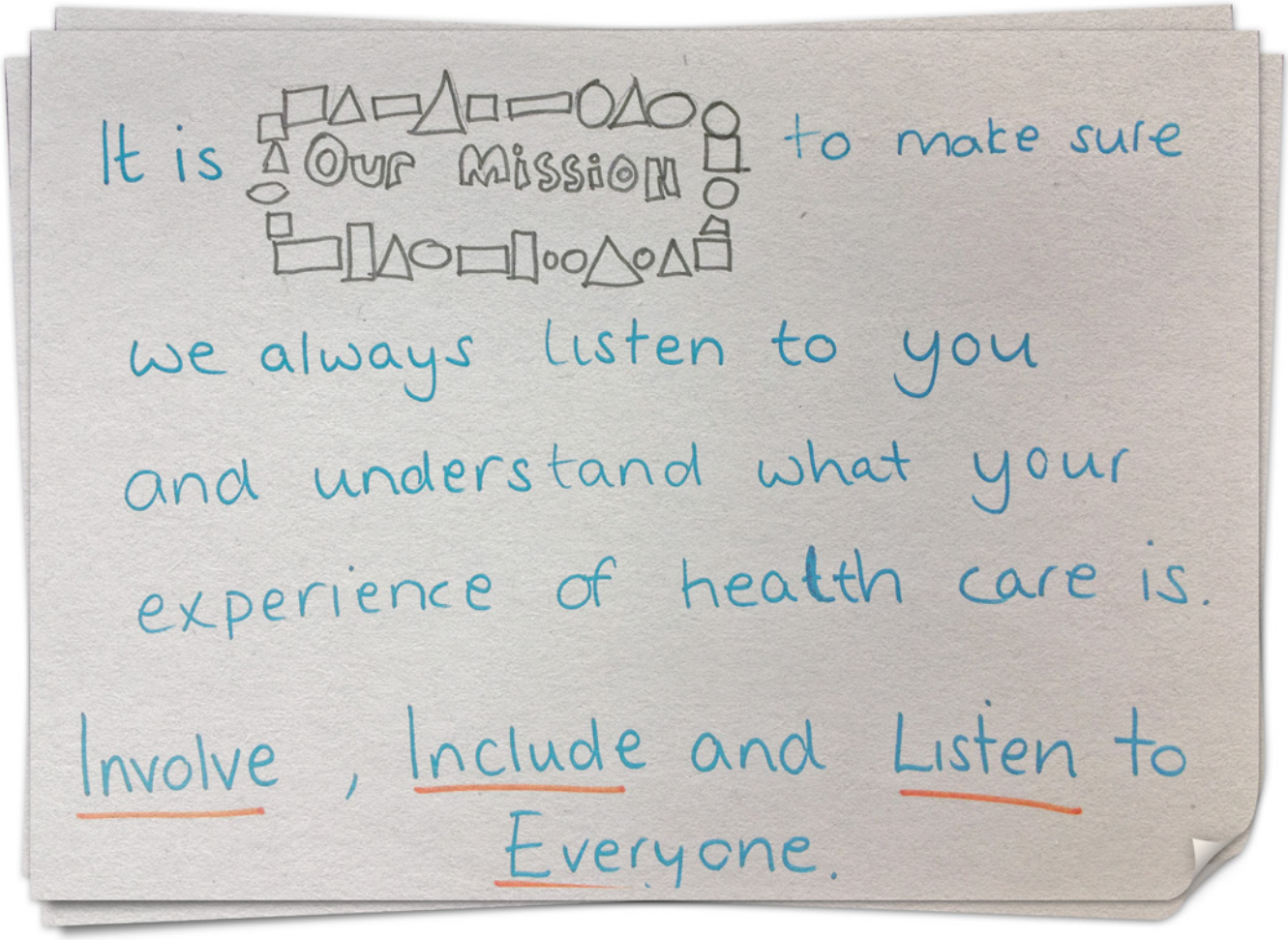
Right: CCHP Participation Strategy booklet

Opposite: Young People's Participation Group Strategy letter





Below: young people's summary of the CCHP participation strategy, called "OUR MISSION". Our mission is the basis of the film *'What goes on in there?'* created by young people to get the strategy message across to children and young people.



Louca-Mai Brady

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Appendix 9: Y-SBNT focus group topic guides and example YP session plan

Embedding Children and Young People's Participation - Topic guide for YSBNT TMG focus group 12/02/15

Aim of the session: to explore TMG members' views on the dynamics of PPI with CYP, learning in practice and what it means to 'embed' CYP's participation in a study of this nature
Who will be involved: Members of TMG, following earlier meeting

Facilitator: Louca-Mai

Start (5 mins)

- Briefly run through info sheet
- Explain that:
    - it will focus on their own ideas and experience, considering firstly YP's involvement in the YSBNT study specifically, and then YP's involvement in research more broadly
    - recognise that not everyone will be able to comment on every topic
- Give out and talk through information sheets and consent forms
- Check it's OK to digitally record, and reassure re: confidentiality
- Reminder of session length – (approx 45 mins)
- *Any questions/concerns?*

Resources: copies of project information sheets & consent forms, handout on SCIE model, digital recorder

Young people's involvement in the YSBNT study (max 20 mins)

- *What were your expectations/understandings about YP's involvement at the start of the project?*
- *What have you learnt about the reality of embedding children and young people's involvement in this study?*
- *What has helped or facilitated YP's involvement in this study?*
    - *What role do you think the TMG has played in supporting/facilitating YP's involvement?*
- *What has hindered or created challenges?*
    - *How have or could these be addressed? What role has the TMG played in creating, identifying or addressing challenges?*
- *What do you think PPI with CYP could/should look like in a full trial?*
- *What have you learnt about the reality of embedding children and young people's involvement in this research more generally?*

- *What more general lessons do you think we can take away from this to inform wider debates about PPI with CYP?*
- *What do you think it means to 'embed' C&YP's involvement in research?*

Summary and close (5 mins):

- *Anything else that you think is important?*
- *Any questions?*

Reassure again regarding confidentiality and remind about next steps

Thank you.

Embedding Children and Young People's Participation - Topic guide for YSBNT TSC focus group 17/02/15

Intro: As well as YP's contributions to the research process, the YSBNT study has provided an opportunity to explore ways in which YP with experience of using SM services can be involved in a study of this nature, hopefully informing a model for PPI in a future full trial and also contributing to the wider evidence base on PPI. As well as being a co-applicant and PPI lead on the YSBNT study, I'm also using young people's involvement in project as a case study for my PhD research.
After agreement from [principal investigator] and [TSC chair] I'd therefore like to briefly explore your views on the involvement of YP, so that I can include a TSC perspective.

Aim of the session: to explore TSC members' views on the dynamics of PPI with CYP, learning in practice and what it means to 'embed' CYP's participation in a study of this nature

Start (5 mins)

- Explain that it will focus on their own ideas and experience, considering firstly YP's involvement in the YSBNT study specifically, and then YP's involvement in research more broadly
- Give out and talk through information sheets and consent forms
- Check it's OK to digitally record, and reassure re: confidentiality
- Reminder of session length – (approx 15 mins)
- *Any questions/concerns?*

Resources: copies of project information sheets & consent forms, digital recorder

Young people's involvement in the YSBNT study (max 20 mins)

- *What were your expectations/understandings about YP's involvement at the start of the project?*
- *What do you think has been learnt about the reality of embedding children and young people's involvement in this study?*
- *What has hindered, and what has helped, YP's involvement in this study?*
- *What role do you think the TSC has played?*
- *What do you think PPI with CYP could/should look like in a full trial?*
- *What have you learnt about the reality of embedding children and young people's involvement in this research more generally?*
    - *What more general lessons do you think we can take away from this to inform wider debates about PPI with CYP?*

Summary and close (5 mins):

- *Anything else that you think is important?*
- *Any questions?*

Reassure again regarding confidentiality and remind about next steps

Thank you

Y-SBNT Young Advisors Meeting. Tues 29/9/15: Facilitators' notes

- **Time and location:** 12.00-16.00. xx
- **Project staff attending:** Louca-Mai, [other PI lead], [researcher 1], [researcher 2]

Time, lead and session aims	**Session info**	**Lead/Resources needed**
11.30-11.45 staff arrive		
Arrivals & lunch **11.45-12.30** **(Louca-Mai & [other PI lead])** Welcome, give name badges, distribute information packs	Welcome, tick off names, give name badges, give information packs to new people, reimburse expenses, collect application forms from new YP and check all signed + consent for recording and photos Contact any YP who have not arrived	Name stickers, Coloured pens Contact information for all yp YNB RA packs to consist of role description, information sheet, team info, sources of support, last newsletter
Introductions (LM) **12.30 – 12.45** Welcome everyone and create comfortable atmosphere. Remind about purpose of the meeting. Explain what the day will cover and answer any questions Establish ground rules for the group	Welcome everyone. *Icebreaker* Explain that the aim of the meeting is: • To get to know each other • Explain a little bit about the project & what we've been doing so far (but not doing very much talking so to ask if have any questions) • Get your thoughts on what we've been finding out from YP taking part in the study • Talk about ways you could be involved in what happens next *Brief introductions: n*ame, where from, role in project (or if have been involved before) why wanted to come to meeting/get involved in project and/or what hoping to get from the day Explain docs in pack & agree ground rules. Remind people that they will be paid for the involvement in the project (£10ph) and that this can either be in vouchers or into bank account, but need to know if they're claiming benefits.	Flipchart + paper & pens Balloons

Brief introduction to the project & PPI (all) **12.45-13.00** Introduce the project and the team- why is this important? Idea behind having a YA group. Defining terms	Very brief overview of project & where we are now ([researcher 1]l) LM: share diagram of research process & where we are now. Refer to information sheet and diagram of research process • Why involve YP in research? (LM & [other PI lead]) • How YP's involvement has informed the project (refer to last newsletter and 'river of experience') • Some of the things we're learning (refer to INVOLVE article) Any questions and comments?	Diagram of research process PEAR guidelines INVOLVE newsletter article Flipchart
How we've involved young people so far **13.00-13.40 (Louca-Mai lead + [researcher 2]/[other PI lead] input in last exercise)**	• Refer back to diagram of the research process: where we are now and what's coming up in (analysis, writing up & dissemination). Will talk later a moment about how they might want to be involved in the next stages but first wanted to give them a chance to get an idea of what analysis might involve: • Introduce qualitative data analysis and ask young people to categorise sweets to give them an idea of how info can be organised in different ways • Give out QA handouts. Looking at the excerpts from interviews with young people who took part in the study, can you see any ways in which this information could be grouped together (themes or patterns)?	Quality Street Excerpts from interview transcripts Qualitative analysis handouts Flipchart & pens
13.40-14.00	**Break (shorter if needed)**	**York to arrange tea, coffee & juice. LM to bring snacks**
Qualitative analysis **14.00 – 15.30** **([researcher 2]/[other PI lead])** Aim: To get YP's input into	YP's knowledge/involvement in ysbnt - summarise main elements Role play on how different yp responded to the interview schedule - thoughts on why this may be? Y-SBNT emerging themes and our interpretation – whether they agree?	

qualitative analysis	Examples of responses based on whether participants thought the intervention was useful - discuss who it might be useful for and why? If improvements could be made and whether we have missed anything important.	
How might YP be involved in the future? 15.30 – 15.45 (Louca-Mai + all)	Talked earlier about how YP have been involved so far, how might they want to be involved in the next stages – eg helping us to write a chapter in the project report about how young people have been involved, designing a lay/YP's summary, speaking at conferences or to other services and YP about the research Thinking back to some of the things we've been learning (ref: earlier discussion and involve newsletter) about how we can involve YP who've used SM services in a project like this in the future	Flipchart and pens
Evaluation **15.45 – 16.00**	• Evaluation dartboards – stick on wall. Give YP stickers and ask them to put one sticker on each dartboard to rate how they feel about each element • Ask them to complete evaluation forms with any comments or feedback on the day (p1) + if they want to stay involved P2) • Thanks everyone for coming. Distribute vouchers and sort expenses	Evaluation dartboards & forms, stickers and blu tac Petty cash and payment forms to acknowledgement payment Vouchers and form to acknowledge payment

- Balloons & Quality sweets (LM)

Equipment needed in room

- Flipcharts + paper & pens

Materials

- Printing (LM to email to [researcher 2] on Mon)
- Blutack, sellotape, normal and coloured pens, coloured post it notes, stickers, folders
- Snacks for break (LM to buy)
- Petty cash (LM)
- Vouchers (LM)

Appendix 10: Example YSBNT meeting notes and YA newsletter

HTA YSBNT study –Notes on Young Advisors meeting 29th September 2015

- There were 3 YP from [North East] at the meeting, all 17: A (who came to the April meeting) and B& C (both new). D was unable to come up from [South West] because she's recently started a new job, or E from [Midlands] as she had a viewing for a new flat, and two other YP from [North East] were also unable to come at the last minute for personal reasons.
- [researcher 1], [researcher 2], [other involvement lead] and Louca-Mai attended the meeting from the research team. The [North East] YP were supported to attend by two project staff from [service], who travelled down with them and joined the meeting at the YP's request.
- The first part of the meeting focused on introductions, a brief overview of project, how we've involved YP in the project so far, and possible next steps. In order to keep the 'talking at' to a minimum we tried to keep this section as brief as possible, giving them the minimum information we thought they needed but also further information in the form of handouts. We also asked the [service] workers to go through the information sheets with the YP on the journey down from [North East].

Introduction to Qualitative Analysis

We introduced the YP to the idea of qualitative data analysis by going through a brief handout explaining key concepts and terminology, and then asking them to categorise sweets to give them an idea of how information can be organised in different ways.

We them gave the YP a selection of quotes from the qualitative interviews with YP, and asked them to see if they could identify any ways in which this information could be grouped together (introducing the idea of coding and themes:

[pictures of young people engaged and activity and data samples excluded from this appendix]

The young advisors took part in three qualitative analysis tasks. For the first activity the young people were given a range of quotes and asked to group them together and suggest a label for each group. They came up with really interesting suggestions which will add to the interpretation of this data for the qualitative findings chapter of the project report.

Examples included [study data excluded]:

THE FIRST THREE THEMES RELATE TO FAMILY LIFE

They feel as if they are being confronted when family members are in the room - FAMILY REACTION

There is a pattern with family life being bad when young people are on drugs - PROBLEMS WITH FAMILY

They all want to keep their mams happy and don't want to worry their family - WORRIES OF THE PARENTS

Action: LM and [other involvement lead] to liaise with [researcher 1] and [researcher 2] re: possibility of further YP's input into qualitative analysis, which could also involve [YP from South West and Midlands unable to attend this meeting]

Action: LM and [other involvement lead] to follow up with YP and [service] staff and consider options for YPs in involvement in further analysis, writing up, dissemination and other activity in the remaining stages at the next TMG.

Evaluation and next steps

We finished the meeting with a discussion on how the YP might want to be be involved in the remainder of the study and what future meetings might look like, alongside evaluation forms and rating various aspects of the meeting using stickers on a series of dartboards (having learnt from the last meeting that it is better to do this when young people are still in the room). Key points:

- All three YP said that they enjoyed the day and xx commented that she had enjoyed it more than the first meeting she attended due to being more actively involved in the work with 'less talking at us'. All YP rated the meeting highly on having a chance to have their say, although one did say that they felt there still needed to be 'less talking at us'.

- **Information:** We kept the introductions to the project and individual sessions to a minimum, with no Powerpoint. This was helped by sending the project workers copies of the information sheets and other background material beforehand and asking them to discuss these with YP on the train down to the meeting. YP fed back that they had probably had the right amount of information to take part but that some of the information and explanations, especially later in the afternoon, were a bit confusing. In a post-meeting review the facilitators agreed that, in future meetings, it would be good to finalise content at least a week beforehand, so that there is time to plan delivery, accessible activities and how the session will 'flow'.

- We put up a flipchart with options for **further involvement** (more analysis, reporting, dissemination and putting together a proposal for a follow-on project) and asked YP to put their names under the areas they were interested in. All three put their names under everything, and this desire for continued involvement was reiterated their evaluation forms and in an email from the project workers feeding back on further discussions on the train home

- **Venue and location:** The YP were happy with both and said that they preferred a meeting away from their home town, as it was nice to go somewhere else. They said that York was better for them than Birmingham as it was a much shorter journey, but that they would have liked a bit more time to look around the city, as two of them had never been before. However it's unlikely that any of these YP would attend future meetings without support from project workers to do so, and two asked to be contacted via the project workers rather than directly. So the workers need to be a key part of planning future meetings.

- **Timing:** We started with lunch and planned a break half way through the meeting, but all three young people said they would have liked more breaks. This will be borne in mind when planning future meetings.

The Y-SBNT Project:
Supporting young people with alcohol & drug problems

This newsletter is for young people who have been involved, or interested in being involved, in the Y-SBNT project and includes:

- an **update on what's been happening** in the project
- some **new opportunities** to get involved in different things, learn new skills and help us plan young people's involvement in future projects
- a **change to the way we pay young people** involved in the project – you can now get an hourly rate instead of vouchers

Have a look and let us know what you think. If you have any questions, our contact details are at the end of this newsletter. If you'd like copies of previous newsletters with more information about the project just let us know and we'll send them to you.

IMPORTANT UPDATE:

We're sending this newsletter to everyone who's been involved in, or said they were interested in, the project at any stage.

If you haven't been in touch with us for a while but, after reading this, are interested in getting involved in some of the opportunities coming up please get in touch and let us know. You may just want to give us your ideas about how we could have involved you better or do things differently next time.

If we don't hear from you, then we'll assume that you no longer want any further involvement with the project and we won't contact you again. If this is the case, that's fine, but we just want to take the chance to say thank you and goodbye. Everyone who's been involved in the project, or said they would be interested in being involved, has helped to shape the project in some way – so thank you!!

Project update

Since the last newsletter in April, the research team have been focused on recruiting young people in the two pilot sites and starting to pilot the YSBNT intervention.

Since the last time we produced a Newsletter we have been very busy testing the new intervention. Having trained the workers in the two services in [West Midlands] and [North East] to deliver Y-SBNT, we then approached young people coming to both services and asked if they were interested in taking part in the study. If young people agree, they receive either the treatment they normally receive from the service or the Y-SBNT intervention over a period of 12 weeks. Which help they receive is decided by chance (like the toss of a coin) so that everyone has the same chance of receiving either form of help. This is done because until we test the treatments we do not know if one form of help is any better than the other. Our researchers [names] have been busy recruiting young people into the study. So far we have recruited a total of 43 young people to the study in both services. Approximately half of the participants are receiving Y-SBNT and half usual treatment. We will finish recruitment at the end of October. Your ideas on how to produce the leaflet we use to introduce the study to young people, how to approach young people and your thoughts and help with materials for the intervention have been invaluable and helped us to recruit well and make good progress. The first month of recruitment was difficult until the project got going and we are now more or less achieving our target of recruiting 10 young people every month. Thank you again for all your help and advice.

What's coming up next?

We're currently planning the next stages of the project and these are some of the ways you could be involved. Let us know what you're interested in, if there's anything else you'd like to do, and how we could involve you best:

- ☆ Contributing to the analysis (for example by commenting on the research team's ideas and early findings and suggesting other things they could look at)
- ☆ Writing a summary of the research findings for young people and others who are interested (to go along with the report written for the funders)
- ☆ Contributing to writing articles about young people's involvement in the research in academic journals and other places
- ☆ Contributing to conference presentations and/or presenting at conferences with members of the research team

☆ Coming to meetings with the project team and steering committee (management group) and helping us to learn about how we could involve young people better in future studies

Newsflash: payment

After talking to a few people, we've decided to change the way we pay young people who are involved in the project as young advisors**. Instead of a £10 or £20 voucher we're now offering payment at a rate of £10 per hour worked on the project.** Hopefully this will make it easier for some people who need to take time off work to be involved, as well as recognising that young advisors are members of the project team. Things to know:

- This payment will be for young people involved in the YSBNT study as Young Advisors on an ongoing basis (i.e. not just one-off consultations)
- We will still also pay travel and related expenses
- Payment can be for attending meetings and/or getting involved in things remotely, provided we agree hours in advance
- Payments can be either vouchers or paid directly into your bank account
- If you're working or on benefits you'll have to declare these payments as income, but we can provide advice and support on how to manage this. You can also choose not to be paid, or to carry on receiving vouchers at the same rate as before

Interested in any or all of this? If so please get in touch and we can tell you more and talk to you about how best to involve you, and any training and support you might need

Thanks again for your involvement and please keep in touch:

⇨ [contact details]

There is an information sheet which tells you more about the project. If you need another copy of this, copies of other newsletters or any other information let Louca-Mai or [public involvement lead 2] know.

Appendix 11: Y-SBNT PPI plans

Youth Social Behaviour and Network Therapy (YSBNT) Study – PPI Plan (v1 29/05/13)

Project lead: [PI]

PPI leads: Louca-Mai Brady & [other PI lead]
PPI sub-group: Louca-Mai, [other PI lead, PI and study coordinator]

All project team to be involved as and when necessary

1. PPI in the YSBNT study

The PPI component of the YSBNT study, as outlined in the proposal, is 'the active involvement of a sample of young people with a history of treatment for substance abuse and a sample of parents of young people with substance abuse problems throughout the research process'. This document outlines plans for patient and public involvement (PPI) in the study.

2. Involvement of children and young people (CYP)

A group of 10-12 young people will be recruited to be actively engaged **throughout the project**. These young people will have used drug and/or alcohol services during the ages of 12-18 but no longer be in treatment, so the likely age range for young advisors will be 15-20 (with a maximum age of 21). These people will form a young advisors' group.

The young advisors' group will be involved in the study in two main ways. Firstly, they will be consulted on the overall study design and the adaptation of the Social Behaviour and Network Therapy for a younger client group. Later on, in phases two and three they will be involved in the project as it develops, including for example in the design of data collection tools, data analysis and interpretation, reporting and dissemination (see 4.below). But the substantive part of the involvement will be in Phase one, when half of the meetings are planned to take place.

Initially [PI], [other PI lead] and Louca-Mai had agreed that the young advisors group should be based in [Midlands]. But, on further discussion and given some potential difficulties with recruiting young ex-service users in this area, there is no specific need for the young advisors' group to be [Midlands]- based. We will therefore explore other areas where we have more contacts and resources, including London and possibly [South-West].

There may also be other activities with young people in the [Midlands] and [North] areas, through the services involved in the project. But these will be separate consultation meetings on the adaptation and, while informed by the PPI, will not be part of the core PPI in the study – which is focused on the young advisors' group.

Recruitment

The young advisors will be recruited through the services with whom they had previously been in contact and/or young people's organisations, and they will have previous experience of accessing substance misuse treatment services, but not currently be in treatment. Recruitment will be supported by an accessible information sheet about the study and their involvement, a simple application form to collate basic information, and by obtaining informed consent from all young advisors. There will be a written agreement or role description with the young person, which clearly states what is expected of them and what they can expect from the project in return.

Methods of involvement

The main method for CYP's involvement in the study will be through **young advisor group meetings** held over the course of the study (with a maximum of 12 meetings planned in total). The meetings will be planned to coincide with key milestones for the project – meaning that, for example, there may be additional meetings early in the study when a key focus will be the adaptation of the intervention and the recruitment of young people to the study itself. The meetings are planned to take place in school holidays or at weekends, last 5-6 hours (including refreshment breaks), but this may be reviewed if this is not convenient or accessible for the young advisors (eg if they want meetings to be shorter and more frequent). These meetings be facilitated by Louca-Mai and [other PI lead] with input from other team members as appropriate, with [PI] and the Research Fellow attending as many meetings as possible, and other team members as needed . A range of activities will be designed to be accessible and engaging for the young group members, while ensuring that the activities also fit the requirements of the study. Young person-friendly and accessible versions of relevant study documents will be developed prior to each meeting.

Second, one or two **young advisors will also be supported to attend trial management and steering committee meetings** (tbc at 27/6 meeting) in order to ensure that young people's views directly inform strategic project decisions. Depending on the wishes of the group these representatives could change over the course of the study. Clear ground rules will be agreed at the start by all involved, based on INVOLVE and other guidance to support this work.

Evaluation of young people's involvement

Each meeting will be evaluated through an anonymous feedback form at the end of the session as well as by inviting comments at the end of sessions through evaluation activities. These evaluations will inform subsequent meetings.

In addition, as part of her PhD on 'embedding children and young people's participation in social care', Louca-Mai will be reflecting with the young advisors, project team and services involved on the process of involving young advisors in the study. Please note – this is *not* an evaluation of the YSBNT intervention, and will not involve talking to any CYP currently in treatment. The focus is on the *processes and impact of participation* rather than the adaptation of the intervention itself.

3. Involvement of parents and carers

We had said in the proposal small number of parents (unrelated to the young people who are recruited) will also be involved in the study through representation on the study Advisory Group. Up to four would be recruited from across the study sites, the focus will be on parents who have experiences of accessing help for themselves or children in the family because of a young person's substance misuse. Again, issues of consent will be adhered to and there will be a contract between the study team and the parents for their involvement. We had said that the main way in which parents will contribute to the study is through representation on the main study Advisory Group, where they will be able to advise and be consulted on all aspects of the study, but this will also be discussed at the meeting on 27/6/

4. PPI during the study phases

a) Phase one

Systematic Review. This could have some limited PPI input (for example seeking the views of the young advisors on search terms, emerging themes etc; discussions with CYP and parent reps at steering group meetings.

Main focus: adaptation of SBNT to the youth context

Young advisors will be supported by Louca-Mai and [other PI lead] to work alongside the research team in order to ensure that the intervention is acceptable and relevant to our target groups, and reflects the views of service users and their families. By closely involving service users and parents in the design of the intervention, we aim to ensure greater retention of young people and social network members during the intervention delivery as well as contributing to the wider evidence base on patient and public involvement.

A clear plan will be developed by the sub-group to identify the agenda and program of work for the meetings with young people and family members, ensuring that this is closely linked into the agenda and program of work for the overall study. Groups will be facilitated, structured and led by members of the project sub-group. Initially the main components of the treatment will be described including (i) the methods used clinically for the identification of family and social support networks, (ii) the introduction of the therapy and the way of working and (iii) the engagement of supportive networks in the treatment process. The views of group members will then inform the development of a youth-focused SBNT, including how to deliver the key components that cover (i) communication, (ii) coping, (iii) behavioural interactions and enhancing activities and (iv) social support. Thus, each of the core and elective elements within the SBNT manual (Copello et al., 2009) will be carefully examined and considered for application within the youth context, drawing on the literature, the PPI work described and also the expert input from Dr McArdle, Professor Gilvarry and Dr Ambegaokar. New sections will be drafted and young people, adult family members

and therapists will be invited to comment on these revisions. In line with our previous work, anonymous material will be used to prepare clinical case-studies and vignettes that will be used to exemplify points and increase accessibility. There may also be additional components that need to be added to the adapted SBNT approach. For example, as referred to above, researchers have pointed to the notable decay in treatment effect for adolescents' drug and alcohol problems (Perepletchikova et al., 2008; Tripodi et al, 2010). Perepletchikova et al. (2008) have accordingly suggested the need to develop innovative intervention strategies to address this problem. There is growing evidence pointing to the effectiveness of continuing post-treatment care – even if quite minimal and delivered by telephone (McKay et al, 2011, 2010; McKay, 2008; Lash et al., 2007, 2011). The team therefore will explore the potential addition of a brief continuing care element to the newly developed SBNT model, employing contact with young people and social network members by mobile phone.

The study manual will combine the most effective components of the SBNT intervention used in earlier studies (Williamson et al., 2007) with elements identified as part of the extensive PPI work conducted during Phase 1. We aim to incorporate comments, views and suggestions from all key stakeholders including young people with substance misuse problems, their family members and therapists delivering the services for young people.

b) Phases two and three

From proposal section 2.1: Research objectives (areas with best potential for PPI underlined)
Phase 2: Feasibility proof of principle Randomised Controlled Trial (RCT) (months 10-28)
v. To demonstrate the feasibility of recruiting young people to a family and network based intervention by recruiting and randomising a minimum of 60 young people to receive the experimental intervention or treatment as usual across two service sites.
vi. To test the feasibility of training staff from existing young people addiction services to deliver the family and social network intervention
vii. To evaluate the level of treatment retention amongst participants randomised to the family and social intervention
viii. To explore through qualitative interviews the participants' views, acceptability and experiences of the intervention and the study process
ix. To establish treatment effectiveness through 3 and 12 month outcome quantitative data
x. To explore cost effectiveness in preparation for a large definitive randomised controlled trial

Phase 3: Analysis and reporting (months 25-30)
xi. To complete analysis of quantitative and qualitative data and produce reports for dissemination

*I would suggest at this stage that we plan in a provisional number of meetings for phases two and three and review PPI plans with young people and steering group members towards the end of phase 1 (when I will be evaluating the impact and outcomes of the phase one PPI for my PhD research).

5. Issues to consider in further development of this plan

- Add risk analysis, budget and distribution of LM and [other PI lead] days. Also still need to clarify whether travel expenses for young people and parents can be reimbursed on attendance through some form of petty cash arrangement.

- Research Fellow and [PI] to attend as many of the young people's meetings as possible, with [PI] coming to the the first one, so that we can ensure that the PPI is closely tied into the study from the start. Meetings will be held in [Midlands] to facilitate this.

Suggested initial milestones

- By 14/6/13 - finalise recruitment materials and agree location for young advisors group
- By 28/6/13 – send recruitment materials to services
- July - recruitment of young advisors
- Late August - First meeting of young advisors group. Focused on introduction to research and to the study
- Second YA meeting in Autumn half term (late October) or earlier on a weekend if preferred by yp/more convenient for project. [PI] to lead session focusing on introducing and getting yp's input into the adaptation
- Then a further 4 meetings around key project stages/milestones during phase one (timing and focus of these meetings to be discussed at June meeting in line with project plans)
- Three-four meetings of young advisors group in phase 2
- Two-three meetings of young advisors group in phase 3

Youth Social Behaviour and Network Therapy (YSBNT) Study – PPI Plan (v4 16/09/14)

PPI leads: Louca-Mai Brady & [other PI lead]

1. PPI in the YSBNT study

The PPI component of the YSBNT study, as outlined in the proposal, is 'the active involvement of a sample of young people with a history of treatment for substance abuse and a sample of parents of young people (YP) with substance abuse problems throughout the research process'. This document outlines revised plans for patient and public involvement (PPI) in the study in the final phases (see earlier versions of this plan for details of plans for, and activities during, phase one).

2. Involvement of children and young people (CYP)- revised plans

Both the trial management group (TMG) and trial steering committee (TSC) have agreed with the PPI leads that the traditional format for PPI originally proposed for the study (a single-location young people's advisory group (YPAG)) is not the right model for working with the young people we wish to engage. This is important learning for the project which, as well as piloting YSBNT is piloting who best to engage YP who do not usually get involved in research. These issues are also being explored as part of Louca-Mai's PhD research. In the meantime we propose the following revisions to the original plans (overall budget and days allocated to PPI will remain the same).

2.1 Continued involvement of young people already engaged in the project

5-6 young people are theoretically still involved in the project, although we have only had a response to communications over the last few months from one of them. We had planned to get as many as possible of these young people together for a meeting in September but, given the lack of response to emails and text messages, will now be unable to do so. We may have to resign ourselves to the fact that these young people are opting out of further involvement, but before we do so we will do the following:

- Draft a newsletter, with input from the project team, outlining activity to date and a timeline for the final stages of the project and send this out in early October 2014. The newsletter will contain details of a revised offer for PPI payment (see point below) and a range of clear options for ways in which YP could be involved in the next stages of the project: for example commenting on analysis and results, writing a YP's summary of research findings, contributing to journal articles and conference presentations, and giving their perspectives on how YP could be involved in a full trial. It has been suggested by the TMG that young people may also be able to interview the research fellows about the experience of running the trial.

- The newsletter will be sent to all nine YP who have been involved in the project to date, in both hard copy and by email, as well as to the project workers who

supported their recruitment. We will make it clear in the cover letter that if we don't hear back from them, we will assume that they no longer want any involvement in the project and will not contact them again. Hopefully this will therefore be a way to say goodbye to some of them, and also to get others to actively opt back in to being involved in the project.

- If YP are interested in continued involvement we will explore with them what they would like to be involved in and how best to do this (eg face-to-face or by email, phone, Skype or social media).

- After considering the INVOLVE, BSMHT and CRN Mental Health guidance on payment for public involvement a proposal by LMB for a revised offer for PPI payment was agreed in principle by the TMG on 10/9/14. The revised offer is that young people involved in the YSBNT study on an ongoing basis, who have signed an agreement to be a Young Advisor, will be offered payment at a rate of £10 per hour they work on YSBNT-related activity, plus travel and subsistence expenses. If young people undertake any work remotely (eg commenting on draft documents, writing sections of articles and reports) the time they will spend on this, and associated payment, will be negotiated in advance. The proposal is cost neutral, as we will be paying fewer people more money.

  Payments will normally be in the form of Love to Shop vouchers but, if YP prefer, can also be paid directly into their bank account via the relevant BSMHT claim form. YP can also choose not to accept payment. If young people are working they will be advised that this income will need to be declared for the purposes of tax and NI, and that it is their responsibility to do this. If they are claiming benefits they will be advised about the necessary rules on earnings, and we will also ensure that their income from the project does not average more than £20 per week. They will be signposted to relevant guidance and sources of information on these matters.

2.2 *Review of young people's involvement*

Alongside attempts to engage, or re-engage young people already involved in the study as outlined above, a review of young people's involvement in the YSBNT study is needed to capture key learning as outlined in the original proposal and protocol, as well as to inform PPI plans for a potential full trial and to wider debates about involving young people in health and social care research. Given the challenges with keeping young people in engaged in the project we propose that LMB and [other PI lead] undertake or facilitate the following during September-December 2014:

- A long slot at the November TMG meeting in which we will explore the values, assumptions and processes of CYP's involvement in the study in order to capture learning thus far and develop a model of PPI for a possible full trial.

- A paper or revised plan based on these discussions will then be developed for the TSC and discussed at the next meeting (date tbc).

- Working with any YP who respond to invitations to remain involved in the project, and getting their perspectives on YP's involvement in the project, a full trial and PPI more generally (eg whether the YPAG model works for some YP better than others).

- Seeking the views of the voluntary sector services and organisations involved in recruitment on the challenges faced in recruiting and retaining YP's involvement in the study, and also explore potential roles the VCS could play in a full trial (eg as a project partner resourced to recruit and support YP's involvement).

- LMB to attend a meeting on 11/10 of [existing YPAG]. This is a group of young people with extensive experience of being involved in a range of health and social care research, primarily clinical trials, with whom LMB has worked in the past. None of this group have, to our knowledge, any direct experience of substance misuse, but it will we think be very helpful to get the perspective of young people who are involved in clinical research on who does, and who doesn't get involved in research and how those who don't traditionally get involved could be supported to do so.

- All these discussions above could then inform the paper which LMB and [other PI lead] have had accepted at the NIHR INVOLVE conference on 26-27/11 on 'Involving children and young people in research: the usual suspects?'. The paper will focus on the inclusiveness, or otherwise, of public involvement with children and young people - who gets involved, who doesn't and why? We will explore participants' ideas on how we can best involve a wide range of children and young people in health & social care research. Feedback and discussions on the paper will then inform our future plans, including an article and other outputs related to PPI with children and YP

- Related to the above, Louca-Mai is also involved – in her capacity as a member of the NIHR advisory group – in a number of fora and discussions around PPI with children and YP, an area which is attracting increasing interest within NIHR and more widely. So all the activity above will inform, and be informed by, wider debates on PPI with CYP.

3. Involvement of parents and carers

We had said in the proposal that a small number of parents (unrelated to the young people who are recruited) will also be involved in the study through representation on the study Advisory Group. In July [other PI lead] ran a focus group with a two adults (woman with foster daughter and mother with adopted son). The discussions were wide ranging and highlighted (at least for these two women) the challenges they faced, and which would influence both their engagement and that of the young people in something like YSBNT; however, both also offered helpful insights in to how to overcome such challenges. Detailed notes from this meeting have been circulated previously. However, as discussed in v3 of this paper, the TMG and TSC have decided against having lay adult representation on the TSC, as this was not felt to be the most meaningful and effective way to involve either YP or parents in the study. Any continued involvement of adults in the remainder of the YSBNT project needs to be discussed by the TMG and guided by the requirements of the project team (note that both adults said they would be keen to be kept updated on the project, and invited to participate further, although neither made any commitment to future involvement).

Appendix 12: Example outputs from Young People's Involvement in Y-SBNT study

This appendix [from study report] summarises seven activities which involved young people, supported with illustrative examples from activities and discussions.

1. <u>Young Advisor meeting, October 2013. Exploring issues emerging from the literature review.</u>

Young people were given cards which summarised features of interventions identified through the literature review, and asked to identify things were important to them and whether there was anything that they would add to the list (bold text highlights comments from the YP).

Cards which the YP stickered as important (in no particular order)	New cards which were added	Cards which were not really discussed or highlighted by the YP
Keeping in touch with me by phone or in person.	Services that are appropriate & are for YP with similar problems. A gap for services for YP aged 18-24, need for transition services .	Worker listens carefully to what I say & understands what I am saying. **Why would they <u>not</u> listen?**
More frequent contact with a service or counsellor if I need it **or want it.**	Suitable workers matched with youths i.e. male-male; female-female; preferences. Mentoring support?	Someone who understands how I feel – they can see things from my point of view.
Preparing me/others for the end of contact with the service/counsellor.	Make sure that the service recognises dual diagnosis and offers the appropriate support.	Giving realistic hope about change.
Flexible help to meet my needs. There are options available & I can choose what will best meet my needs. **Help with everyday things like budgeting & shopping.**	Alternative therapies e.g. homeopathy, acupuncture, seeds, shiatsu etc.	Not having to wait long to get help or to have counselling sessions.
Worker understands me & what I have to say. **Listens! It's not just a form filling exercise.**	Having an overall structure to the service & a clear ending.	Being rewarded for attendance &/or good progress. **Why should we be rewarded?**
Good communication which has a clear goal & is focused on what's important.		Using text, Twitter etc. To keep in touch. **Keep it formal by text, phone; do not use social media.**
Having a good relationship with the counsellor.		Help that focuses on my strengths rather than negative or bad things.
Setting goals & targets to achieve them.		An individualised service that is tailored to my needs, it's not a 'one size fits all'. **One YP mentioned the need for out of hours support.**

2. <u>Young Advisors meeting, October 2013. Network exercise.</u>

Young people were asked to think about important people in their lives and whether they were helpful/supportive or unhelpful/unsupportive to their recovery, and record this on two pieces of flipchart paper using post-it notes. One young person suggested a third 'neutral' category of people who were neither helpful nor unhelpful.

Important people: who they are & how they are helpful/supportive	**Impartial – they're not really helpful or unhelpful**	**Important people: who they are & how they are unhelpful/unsupportive**
Supportive GPs willing to suggest helpful ideas. Supportive family that understand, willing to help. Getting involved in e.g. work, college, voluntary work etc., new friends, activities etc. Different types of help from different workers re different issues. supportive partner. Friends with the same problems as you & are willing to stop. A really helpful key worker that has looked at me as an individual and helped me to change my life. Friends that do not use. Supportive & educated hostel staff.	Family that know about the issue but do not take an active part in your use.	Other users in group sessions or work etc. They can suggest going outside for joint/using. Fellow family user – because they might not want to stop and you do. Friends that are going through the same problems as you but aren't willing to stop. Workers who are disinterested or not helping, just there! A friend who is staying with me and smoking cannabis in my house when I'm trying to quit.

3. Young Advisors meeting, December 2013. Key components of SBNT

Young people were presented with the key components of SBNT (the adult intervention) and asked to think about how they might be important or relevant to young people.

Component	What YP wrote
That I spend less time with those who are not helpful or encourage drug & alcohol use.	Although it's hard to cut off your friends completely, it was important to try & stay away from friends who use. Most of my friends used drugs so it can also isolate people. Solution: going to groups with YP who want to change their drug use. Time away from drug users/stressful situations.
That we communicate well & openly & we solved problems together.	Everyone involved needs to remain involved, and in contact with everyone else, and needs to be on the same page as everyone else to ensure the correct support is given. Consistency is important. Trust is important, if you can trust people you can be honest about the problems you are facing. All services working with the person need to stay in contact & also keep the person they're working with included in decisions/stuff that affects them.
We all have positive views of the value of supporting each other.	It's nice to help people & be able to make a change to someone's life. I think it's important people can see the value of supporting each other and the benefits the person they are supporting will get – there needs to be advice/support for the person helping the YP with an issue.
We all have the same understanding of the problem.	We all have our own thoughts on drugs/alcohol but we all need the understanding what's best for the young person.
That we all know specifically what we are doing to support each other.	All people involved need to be clear on what is going to help the person. All understand and know their role and involvement in the support of a young person, and how to communicate with each other.
That I manage to get over barriers that get in the way of getting support from others. **YP identified trust as a barrier.**	It is important you can trust them, you need to be reassured as many YP may have been through many services, been let down by family/friends and have trust issues. Some young people aren't close to parents or other support that may be very beneficial to them and maybe the first stage is to build relationships.
That I know how to ask and to give emotional, practical & social support.	It's important to know where to get support/ask for advice & after sorting your own stuff out be able to support & help others through their issues. Support also needs to be <u>offered</u> as much as possible as some people will just not ask for support or just support on some topics/problems.
That those who support me have support themselves.	Some people that are supporting young people may need support themselves. Example: a parent may want to support their child but may be a user themselves and may need/have an adult service to support them.
That I spend time doing fun things with positive friends and family members.	It is important to have fun, have a hobby that you can enjoy with friends/family. Mediation may be needed to get to this point. It is good to have fun with friends & family away from all the 'crap'. Everything costs money! Have a list of open days and free activities for families to do for fun.

4. <u>March 2014. Excerpts from an open letter written by a YP for Y-SBNT training materials</u>

To an important person in my life,

I want to try and help you understand drugs. I'm not going to try and persuade you that drugs are great or that I don't have problems, because I know that both statements are wrong.

..... You've supported me through many dark times and I can see that you care deeply for me (as I, you). However, your lack of experience with drugs completely dominates your treatment of me and I want you to know that it's not helping me. You're a caring, strong and loyal person, but you seem to think I am oblivious to the dangers surrounding drugs and that's simply not true.

Growing up in a family with drug, alcohol, mental health and financial problems, I'm fully aware of the effect drugs can have.....I think about it every day and in fact it still affects me today.....

At the end of the day, your strict rules and dictatorship will never motivate me to stop using....you are just further demonstrating not only your lack of understanding, but your lack of desire to understand. I don't want you to sit back and let me smoke weed 24/7 either. Simply display an interest in my perspective. That way, I'll know that you're trying and that you see me as an equal; two things that are necessary for me to want to listen to you.....

....Maybe instead of judging me, you could have come with me to my drug counselling. Instead of making a formal complaint about my social worker because she knew and didn't tell you, you could have recognised that she could see I was responsible and mature....

....There are a number of ways you could have handled the situation in a much more helpful and supportive way. Don't ban me from smoking weed entirely, straight away. Talk to me about the feelings that make me want to be stoned all day and work with me to identify replacement activities, or distractions..... perhaps an incentive would have helped. Something small but worth it, to keep me going when all I want is a joint, and to show me that you recognise how hard I've worked when I cut down.

I can't stress enough how your totalitarian approach to me doing drugs made me feel. I felt misunderstood, patronised and so, so guilty. These three emotions only work to strengthen my desire to smoke, and lessen my willpower to stop. Threatening to kick me out and shouting at me for having weed in my room in front of the neighbours was very damaging, and it pushed you and me further apart. I need to be able to freely talk to you if I'm to make progress.

After everything, I completely understand why you acted the way you did.....You care about me and you genuinely thought you were doing the right thing.....

Thank you for reading.

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5. Consultation meeting, March 2014. Comments on worksheet.

Young people discussed a draft worksheet for practitioners, which suggested areas of life young people might want to work on during treatment sessions in the Y-SBNT pilot. Feedback included:

- 'Drug and alcohol use' needs to come first, but they liked the idea that this wasn't the only area to be worked on.
- 'Legal/crime' makes an assumption that all YP accessing services were engaged in criminal activity; it won't be relevant to everyone and could put people off. They suggested a more general category around what YP were doing ('regular/recent activity'), including education/work, accessing other services & legal/criminal activity.
- 'Family relationships' is important but could be problematic for some YP who are estranged from their families or whose parents have problems of their own. Also where do girlfriends/boyfriends or other relationships fit into these categories? – they are often key enablers/barriers to recovery. How about 'family and other significant relationships'?
- 'Social life and friends' could be broader; how about 'free time'.
- They suggested a fifth category of 'living arrangements'. Many of the YP we've spoken to have lived in hostels or institutional care; where and how YP live can be key to recovery.

6. Young Advisors meeting, April 2015. Discussion on retention and engagement.

Young people were asked to pair up and record their thoughts on each of the questions below using post-its. We then put the post-it notes (text written in blue) on flipchart paper and had a whole group discussion (text written in red). Responses included:

1) What is the best way of keeping in touch with young people taking part in the study?

- How do we avoid them feeling too pressured by this contact? Do you think asking if we can contact young people on social media (e.g. Facebook, Twitter) is ok? What about text, WhatsApp or letter? How would you feel about a researcher contacting you through these methods?

- *'consistency and persistence I think is the best way to stay in contact. Be flexible'*
- *'ask them when & how is the best way to contact them'*
- *'facebook, text, phone, email, & letter'*
- *'family, friends, carers, & strangers'*
- *'facebook-work = kept separate'*
- *Well maybe in that bigger gap [between 3-12 months] phone people two times a month instead of once just to jog their memory because that is quite a long time for just one phone call.*

Young people agreed that having a list of preferred ways to be contacted (including social media such as WhatsApp and Twitter) should be included as part of the consent procedure.

2) Payment: Do you think a £10 voucher for a one hour interview with a researcher is enough?

- What sort of rewards would make you want to take part/stay involved in a study like this?
- *'I suppose the YP has to question their motives. I personally think it's ok. Bearing in mind majority of YP would like to be paid in cash due to financial difficulties'*
- *'money instead of vouchers, activities (e.g. Blackpool, Alton Towers)*

You could get a voucher for coming in and you know then when you come back for the final one, everybody that have done it like, could go on a trip.

YP also suggested a competition or prize draw.

3) Social network involvement: Would you be happy to have important people in your life taking part in your treatment sessions?

- What do you think would help other young people to have important people involved in their treatment?

- *'I suppose to express the importance of positive people in one's life and to help the YP to identify positive people and if YP can't identify positive people, introduce them to fellowships that might also help them & benefit them in more than one way'*
- *'people would be less likely to talk about drug and alcohol problems with important people in the session'*

7. Young Advisors meeting, September 2015. Input into qualitative analysis.

Young people were given a selection of quotes from the qualitative interviews with YP, and asked to identify any ways in which this information could be grouped together. Examples included:

THE FIRST THREE THEMES RELATE TO FAMILY LIFE

- They feel as if they are being confronted when family members are in the room - FAMILY REACTION.
- There is a pattern with family life being bad when young people are on drugs - PROBLEMS WITH FAMILY.
- They all want to keep their mams happy and don't want to worry their family - WORRIES OF THE PARENTS.

Following a role play activity in which two transcripts were read out by researchers and YP the group then reflected on why there may be differences in responses. YP mentioned the following:

- *I think they need to take the time to get to know the person and not put an act on as if they really care they have to actually really care about the person.*
- *You have got to be ready to engage with someone.*
- *You would want to go to see someone like (Y-SBNT therapist). She just understands, she just loves her job and she just cares. Like she just doesn't give up until she gets somewhere with you, you know what I mean, she's just lovely.*

The final part of the session involved getting the young peoples' interpretations and insights into the initial themes identified from the data analysis. The young people provided their feedback on the themes and suggested alternative headings including one they titled 'realisation':

- *Cos you don't even realise, like you don't realise what you are doing and you don't realise how bad it is until the penny drops.*
- *Like ending up in hospital or getting a criminal record or ending up being like really ill.*
- *That's realisation – having to move away from existing friends.*
- *You could be getting forced to go or doing it for other people (getting help) but then actually end up wanting to do it yourself.*

Appendix 13: Summary of young people's involvement and how this informed the Y-SBNT study

Date	YP involved	Meeting/ contact	PPI activity	How PPI activity informed the study
13 September 2013	Attended meeting: F1 & F2 YP in contact prior to mtg: 6	London (LMB & [other PPI lead])	Young advisor (YA) mtg. Introduction to the study & PPI. Discussion of ways in which YP might like to be involved.	General learning about YP views on getting help & the potential of involving families and networks. Also learning about how we could involve the YP attending and others going forward. Discussions informed development of intervention and supporting materials. The materials generated from discussion with young people that enhanced the adapted intervention included: examples from the young people in terms of processes perceived as important to obtain social network support; good and bad aspects of services; examples of social network diagrams from young people that were used to develop examples in the manual; an example of an open letter from a young person to a family member included as an appendix to the manual. In addition, the discussion about how to present the intervention to young people and how to introduce the idea of social network support were incorporated into the materials that were used for therapists' training.
24 October 2013	Attended meeting: F1 & F3 YP in contact prior to mtg: 4	London (LMB, [other PPI lead and 2 members of research team])	YA mtg. Discussion, about YP's views on the YSBNT study and intervention. Exercise to explore YP's perceptions of what makes a good and bad experience of a service, what facilitates them engaging with, and staying engaged with, services. Intro to idea of networks and exercise to explore who YP perceived to be important in their lives, who supported them with regards to their SM, and why and when they found people unhelpful or unsupportive. Discussion on first draft of trial leaflet and information sheet.	General learning about YP views on getting help & the potential of involving families and networks. Discussions informed development of intervention and supporting materials as presented above. Trial leaflet and information sheet were significantly revised as a result of YP input, including wording, presentation and the use of simple language.
3 December 2013	Attended meeting: F3, F4 YP in contact	London (LMB, [other PPI lead and 2 members of research team])	YA mtg. Update on project/activity to date. Discussion of revised recruitment materials following last meeting & newsletter sent to YP after meetings. Exercise to explore YP's views on of the	General learning about YP views on getting help, the potential of involving families and networks, and of things to think about when developing the new intervention. Discussions informed development of intervention and supporting materials as already outlined above. Comments influenced style and content of future newsletters.

	prior to mtg: 5		mechanisms of change involved in Y-SBNT. Discussion of YP's thoughts and responses to the key components of YSBNT and their relevance to YP.	
15th January 2014	F2	London (LMB)	1:1 mtg in lieu of F2 attending the December 2013 meeting.	Incorporated into outcomes from Dec 2013 YA meeting above.
23 January 2014	Attended meeting: F5, F6, M1	[south west] (other PPI lead & YP's support worker)	YA mtg. General discussion about the project, the intervention & how YP could get involved. Repeated 2 exercises completed with other YP (sort card re helpful interventions and networks – see above for details of exercises and their rationale).	General learning about YP views on getting help, the potential of involving families and networks, and of things to think about when developing the new intervention. Discussions informed development of intervention and supporting materials as already described. *F5 remained engaged since this meeting; attempts were made to keep in touch with F6 & MI but they did not remain engaged.
5 March 2014	F5	[south west] (other PPI lead)	1:1 mtg. Supported YP to write an open letter to someone important to her outlining how that person has supported her to date, when they have been unhelpful & what they could have done differently to support YP. Discussed & got content for newsletter to be circulated to all YP engaged with the PPI element of the study to date.	Open letter included with intervention materials as an example of the type of communication strategy that could be used as part of the intervention work with young people. Quotes from YP used in newsletter; also in later publications (conferences and article).
19 March 2014	F5	[south west] (other PPI lead)	1:1 mtg. Asked YP for their views on a 'setting goals worksheet' drafted by other team members for the intervention manual (used to explore areas of life YP might want to work on during YSBNT treatment sessions). Asked YP to draw their social support diagram (a core component of the intervention) to detail all those who are important to them, who has been important with regards to support (and how) and who has not (and why not).	Setting goals worksheet revised in light of comments. The goal setting worksheet was adapted to the areas that the young people felt were relevant and important for this client group. The social network diagrams developed informed examples that were used for training and training materials once details were carefully anonymised.
6 March 2014	M2, M3	[south west] (+ LMB & 2 YP's support workers)	General introduction to the project and PPI. Exercise to map YPs social networks. Commenting on a draft 'setting goals' worksheet to be used to explore areas of life YP might want to work on during YSBNT treatment sessions.	General learning about YP views on getting help, the potential of involving families and networks, and of things to think about when developing the new intervention. Discussions informed development of intervention and supporting materials. 'Setting goals' worksheet revised in light of YP's feedback. Note that network exercises completed at several of the above meetings used to develop sample YP networks which were included as part of

				intervention materials. *Both YP said they were interested in further involvement but contact then faded with them and project workers despite several attempts to contact them and keep them updated on opportunities.
24 April 2014	F5	[south west] (+ PT, BD & other PPI lead)	The 2 Research Fellows spent some time with YP, piloting all the trial questionnaires and how they would be introduced to YP in the trial, and discussing any queries/comments etc. raised by the YP.	Informed Research Fellows' data collection processes with YP. See 30/4/14 meeting below
30 April 2014	None directly	Cutting Edge conference (LMB & other PPI lead)	Conference presentation to SM project workers based in the SW about the YSBNT project and some of the emerging learning from PPI about engaging and working with YP who use SM services.	Raised awareness of the study, and our attempts to involve CYP in the research. Useful feedback from project workers and others present about working with this 'hard to reach' group of CYP
30 April 2014	F7, F8	Birmingham (+ PT & DB)	Meetings w YP to pilot questionnaires – see 24 April.	This and 24/4 meeting helped researchers to come to a better understanding of how they could be more consistent in their approach to both administering the questionnaires, and also introducing the assessment. The YP's feedback helped to identify the most effective way to get information about the assessment across to study participants (e.g. mentioning at the start they would have to complete a consent form to take part etc.). Going through the TLFB with YP gave the researchers an appreciation of the importance of building up a picture of the young person's recent life before asking about their substance use, and suggested some useful prompts for doing this. For both the TLFB and IPDA the YP highlighted potential issues with recall and how to best capture poly-drug use, as well as giving insights into potential difficulties with some of the assessments and the need for consistent prompts. Also on the IPDA the YP highlighted that difficulties with some of the questions for professionals which were also taken into account
1 May 2015	YP	Birmingham (+ DB)	Meetings w YP to pilot questionnaires – see 24 April.	
6 May 2014	F5	[south west] (+ other PPI lead)	An update meeting to keep engaged – updated YP on the project and how YP could get involved; gave her the opportunity to ask questions etc.	Update meetings. General discussions informed learning of research team about issues around involving this group of YP e.g. payment of YP, future involvement of YP in the project, measuring drug use.
12 June 2014	F5	[south west] (+ other PPI lead)	Update meeting to keep YP engaged. At the request of other members of the research	

			team discussed measuring drug use, particularly when YP are using multiple drugs and do not always know what they are taking.	
22 September 2014	F5	[south west] (+ other PPI lead & LMB)	Update mtg. Discussed proposed changes to involvement of YP in the project including increase in payment rate, ideas for future meetings and involvement in next stages of project Also discussed some of the challenges faced in recruiting and retaining YP for PPI in the study & YP's thoughts on how we could do things differently in the rest of the study and a possible full trial.	Discussions informed revised plan for YSBNT PPI and subsequent involvement of YP.
12 November 2014	F7	Birmingham (+ LMB & other PPI lead)	Brief introduction mtg to tell YP a bit about the project and PPI and see if she was interested in being involved.	A new young advisor.
17 November 2014	F7	INVOLVE conference (+ LMB & other PPI lead)	Conference presentation about emerging learning from involving YP in the YSBNT study. YP talked about her experience of being involved and why she thought it was important for YP with direct experience of SM services to be involved in a study like YSBNT.	Raised awareness of PPI in the YSBNT study and our efforts to involve 'less frequently heard' YP in clinical research. Also raised issues of who does and doesn't get involved in research and whether the usual model for PPI with YP (standing advisory groups) may work better for some YP than others. Presentation led to invitation to write article (which we co-authored with F5 & F7) for INVOLVE newsletter, which equally raised awareness.
Jan/Feb 2015	F7	Phone conversation and 1:1 meeting in Birmingham	Discussions about payment and revised payment for PPI + opportunities and interest in involvement in next stages of research. Also contribution to INVOLVE newsletter article & possible attendance at future TMG and TSC meetings. Discussed qualitative interview schedule.	Article submitted to INVOLVE with contributions from F5 & F7. F7 was due to attend both TSC and TMG meetings in 02/15 but was unable to do so due to illness/other issues. Comments on qualitative interview schedule fed back and incorporated into revised schedule where possible (feedback on what was and wasn't changed then fed back to S).
1 April 2015 YP in contact prior to mtg: 6	F7, F9, F10 & M4	Birmingham (+ LMB, AC, DB, PT & 2 project workers)	YA mtg. Overview of project, how we've involved YP in the project so far, how this involvement has informed the project to date and emerging learning on YP's involvement. Session led by Research Fellows on retention and engagement. The YP were asked to pair up and, with support from the therapists, record their thoughts on the best way of	Discussions & exercises informed research team learning about future involvement of YP in the remainder of the study and a possible full trial. Discussions on retention and engagement: the YP reported that they preferred contact with one key person whom they trusted. The researchers used this model and liaised through therapists with YP still engaged with the service. This was a positive experience and resulted in positive feedback from staff involved:

			keeping in touch with young people taking part in the study, payment and the presence of social network members in treatment sessions. Discussion on how YP might be involved in the remainder of the study and how involvement might look in a full trial.	*"You'll be pleased to know one of my YP whom you interviewed has just asked when you were coming back to re-interview him"* TAU therapist
Ongoing contact	Mainly F5 & F7 but some contact with YP from North East	Via post, text, phone and email	All YP were sent letters and newsletter about the 4/15 and 9/15 meetings and opportunities for involvement in analysis, writing up and dissemination. Followed up with emails, texts and contact with services as applicable. Additional contact with F5 & F7 mainly to keep in touch and keep them updated on project & opportunities for involvement.	One YP (F7) contributed to the draft PPI chapter via a phone interview. This was recorded and quotes from this used, with her consent, in the chapter. Material from the meeting with F5 in September 2014 were also used in the draft chapter in a similar fashion
29 September 2015	Attended meeting: F9, F11 & M5 YP in contact prior to mtg: 7	York (LMB, other PPI lead, 2 members of research team & 2 project workers)	YA mtg focused on getting YP's input into qualitative analysis. Introduced the YP to the key concepts in qualitative data analysis and then gave them a selection of quotes from the qualitative interviews with YP and asked them to see if they could identify any ways in which this information could be grouped together. Research Fellow then lead a session getting YP's input on emerging findings from the analysis to date. The meeting ended with an evaluation and discussion about if and how YP might want to be involved in writing up & dissemination	Further explanation provided by the young advisors was used to help interpret key quotes, for example, why some young people appeared to benefit from the intervention whilst others did not. Also the themes that the young advisors suggested were integrated with the researchers' initial themes to add further descriptive detail to the qualitative analysis. Evaluation feedback was used to inform plans for location, timing and content of future meetings as well as to inform a model of how YP who have used substance misuse studies might be involved in other studies
12 November 2015	F5	[south west] (other PPI lead)	General catch-up, as this YP hadn't been able to be involved in the project for over a year. Then discussion focused on draft of chapter 8 of project report, which YP had spent time reading and annotating prior to the meeting.	The YP's additions and amendments were almost all incorporated into the next draft of the chapter, adding a valuable YP's perspective. The YP was also given feedback on how and where each of her points and additions had been incorporated into the chapter.
26 November 2015	Attended meeting: F7, F11 and F12	York (LMB, other PPI lead, member of research team	YA mtg focused on getting YP's on draft report and quantitative analysis. This activity focused on chapter 8 and their experience of being involved in the study and views on the emerging learning recommendations. Young	Young people's feedback and additions on the draft report were incorporated into the final drafts of chapter 8. Young people's feedback will be used when discussing certain aspects of the data and when the research team are considering interpretation of

		& 1 project worker)	people were given an overview of the report and invited to look at sections of the report which had been enlarged and put on flipcharts on the walls. They were asked to add comments, amendments and additions onto this text. The young people also commented on findings emerging from the quantitative analysis, with their comments and questions fed back to the statisticians. The young people also started to discuss their ideas for a lay summary, which we hope to produce with them in early 2016, and contributed to a consultation exercise for NIHR INVOLVE on the development of 'top tips' for researchers planning to involve young people in health and social care research.	the results. Plans for a lay summary will be agreed with the TMG and TSC and this is something we hope to take forward in early 2016. YP's comments on 'top tips' fed back to INVOLVE and will inform the final draft of these guidelines

Summary of engagement

- A total of 17 young people were involved as young advisors in some capacity.
- The young people came from five areas of England (the West Midlands, the North East and West of England, London and Oxfordshire).
- The 17 young people included 12 female and five male, ranging in age from 16-21 with an average age of 18
- We met ten young people once, five twice, and two on five or more occasions.
- Over the course of the study we held a total of 20 face-to-face meetings with young people. In between meetings contact was maintained by post, text messages, emails or phone calls depending on the preferences of the young people involved.
- Seven newsletters were sent to young people during the course of the study with updates on the project, information about how young people had been involved and upcoming opportunities.

Appendix 14: Summary of material used in analysis

Case Study 1 - CCHP

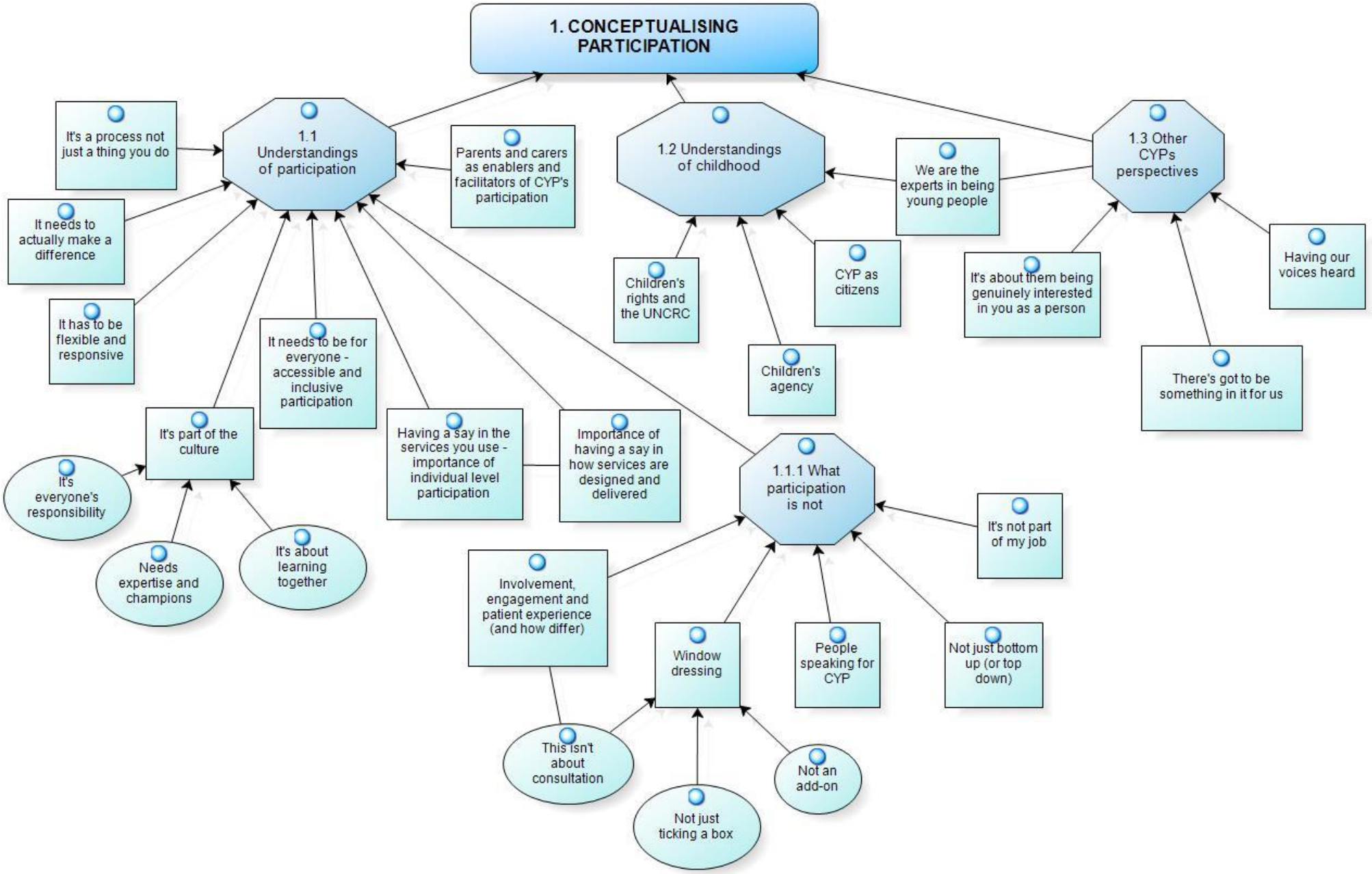
Source	Activities	Number of participants	Material generated for analysis
Initial meeting with participation manager, Jan 2013	Informal conversation	1	My notes from meeting
CCCHP 'celebrating participation' event, May 2013	50 minute session introducing PhD research and understandings of 'embedded participation	72 professionals, 6 YP, 3 parents	My notes from meeting, CCHP write-up of event
'Core group' meetings with CCHP managers	Discussion about plans for and progress of research at 8 meetings between July 2013 and July 2015	3-5 participants at each meeting	My notes from meeting
Staff participation strategy workshop 1.1, September 2013	Small and large group discussions, creative activities	14 professionals	Transcribed recording, notes from meeting, flipcharts and photographs of creative outputs
Young people's workshop, Oct 2013	As workshop 1 above	7 young people and 3 support staff	As workshop 1 above
Staff participation strategy workshop 1.2, November 2013	As workshop 1 above	13 professionals	As workshop 1 above
Participation strategy workshop 1.3, December 2013	As workshop 1 above	12 professionals, 6 young people	As workshop 1 above
Participation strategy workshop 1.4, February 2014	As workshop 1 above	11 professionals, 6 young people	As workshop 1 above
Parent focus group 1, Oct 2013	Discussion around topic guide	4 parents, 1 professional, 1 young person	Transcribed recording
CCHP operational management focus group, Nov 2013	Discussion around topic guide	12 professionals	Transcribed recording
Clinical Commissioning group, Dec 2013	Discussion around topic guide	10 professionals	Transcribed recording
CCHP clinical governance focus group, Jan 2014	Discussion around topic guide	13 professionals	Transcribed recording
CCHP event showcasing 'our participation story',	Presentations from participants on participation strategy and film	26 professionals, six young people	Presentations, photographs of story boards and other

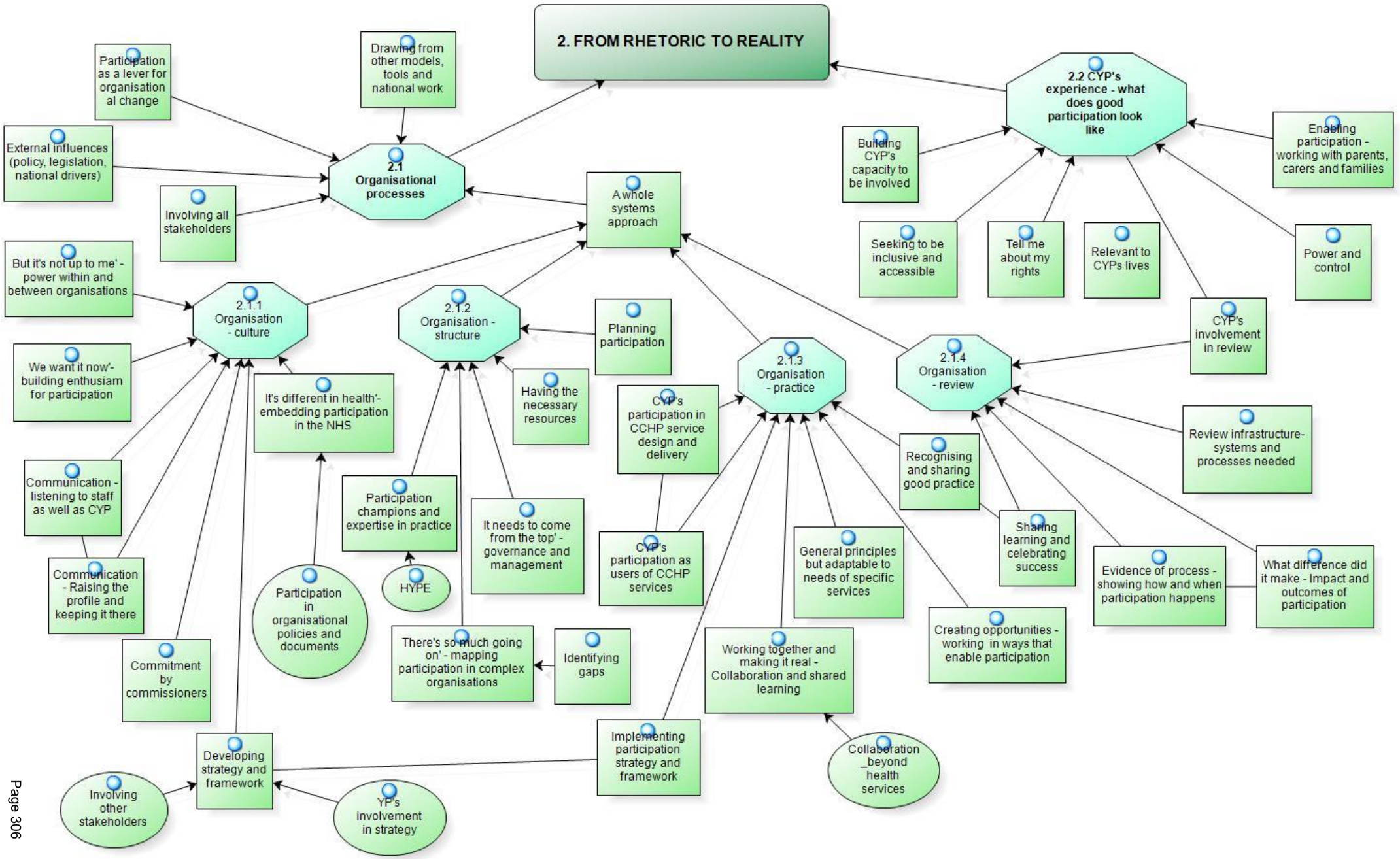
April 2014			materials produced by young people
CCHP CAMHS and allied health professionals focus group, May 2014	Discussion around topic guide	6 professionals	Transcribed recording
Participation workshop 2.1, May 2014	Small and large group discussions and exercises	10 professionals	Transcribed recording of group conversations, flipcharts and meeting notes
Participation workshop 2.2, June 2014	Small and large group discussions and exercises	9 professionals	As workshop 2.1 above
Participation workshop 2.3, June 2014	Small and large group discussions and exercises	8 professionals	As workshop 2.1 above
Parent focus group 2, July 2014	Discussion around topic guide	3 parents, 3 professionals, 1 young person	Transcribed recording
Voluntary sector CYP's network meeting, Oct 2014	Discussion on emerging findings from CCHP and wider commissioning context	Approx 30 professionals	Recording of discussion
Meeting to feedback on progress, reflect on learning from project and agree next steps, Oct 2014	Small and large group discussions, exercises and presentations	13 professionals, 2 young people	Transcribed recording of group conversations, flipcharts, presentations and meeting notes
Meetings with staff and young people to discuss emerging findings, June 2015	Small and large group discussions and exercises	7 professionals, 5 young people	Transcribed recording of group conversations, flipcharts and meeting notes
Emails and journal entries	Correspondence and my observations throughout the process	Various	Source of material to document process and my role in this

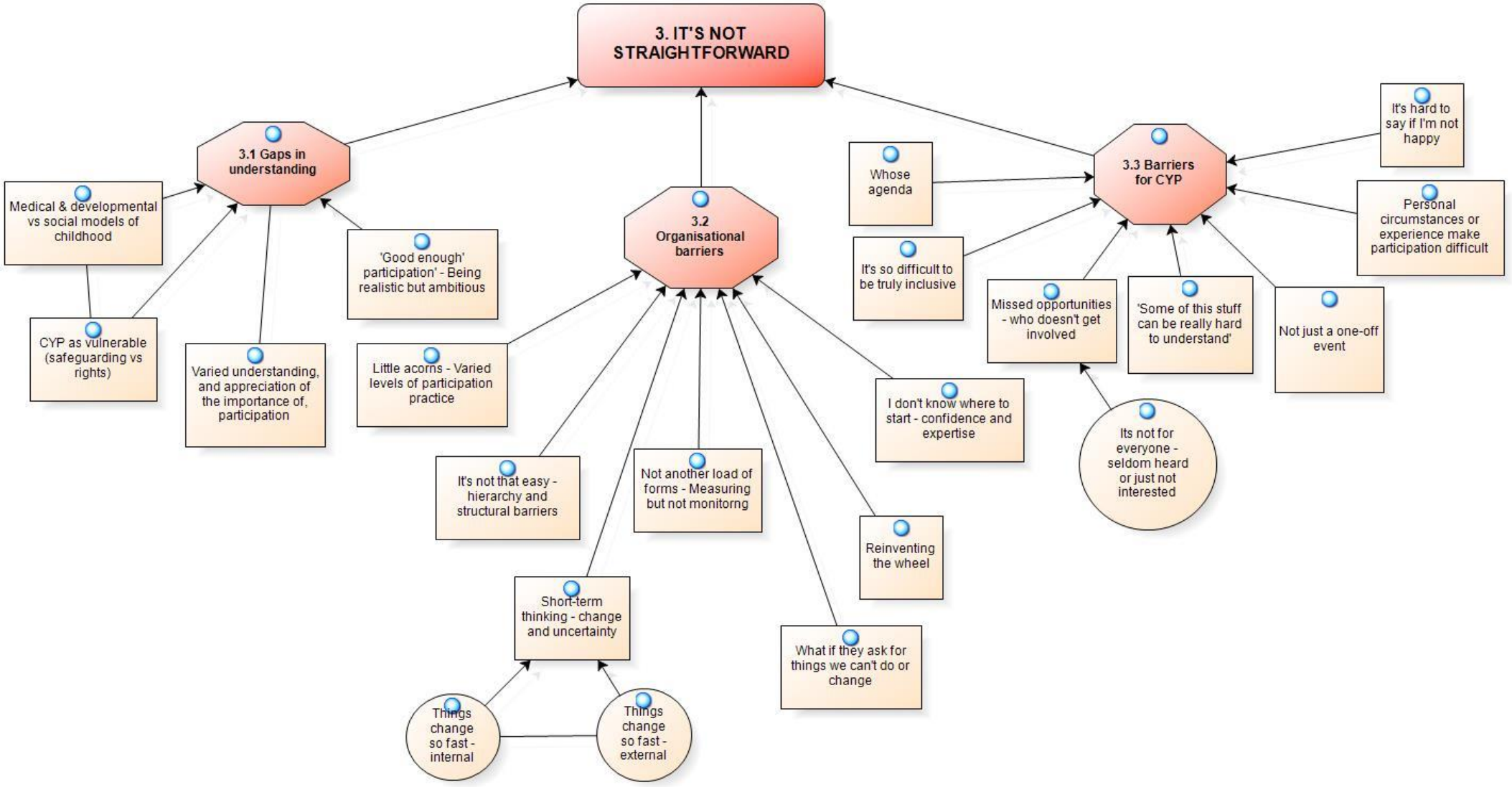
Case Study 2 – Y-SBNT study

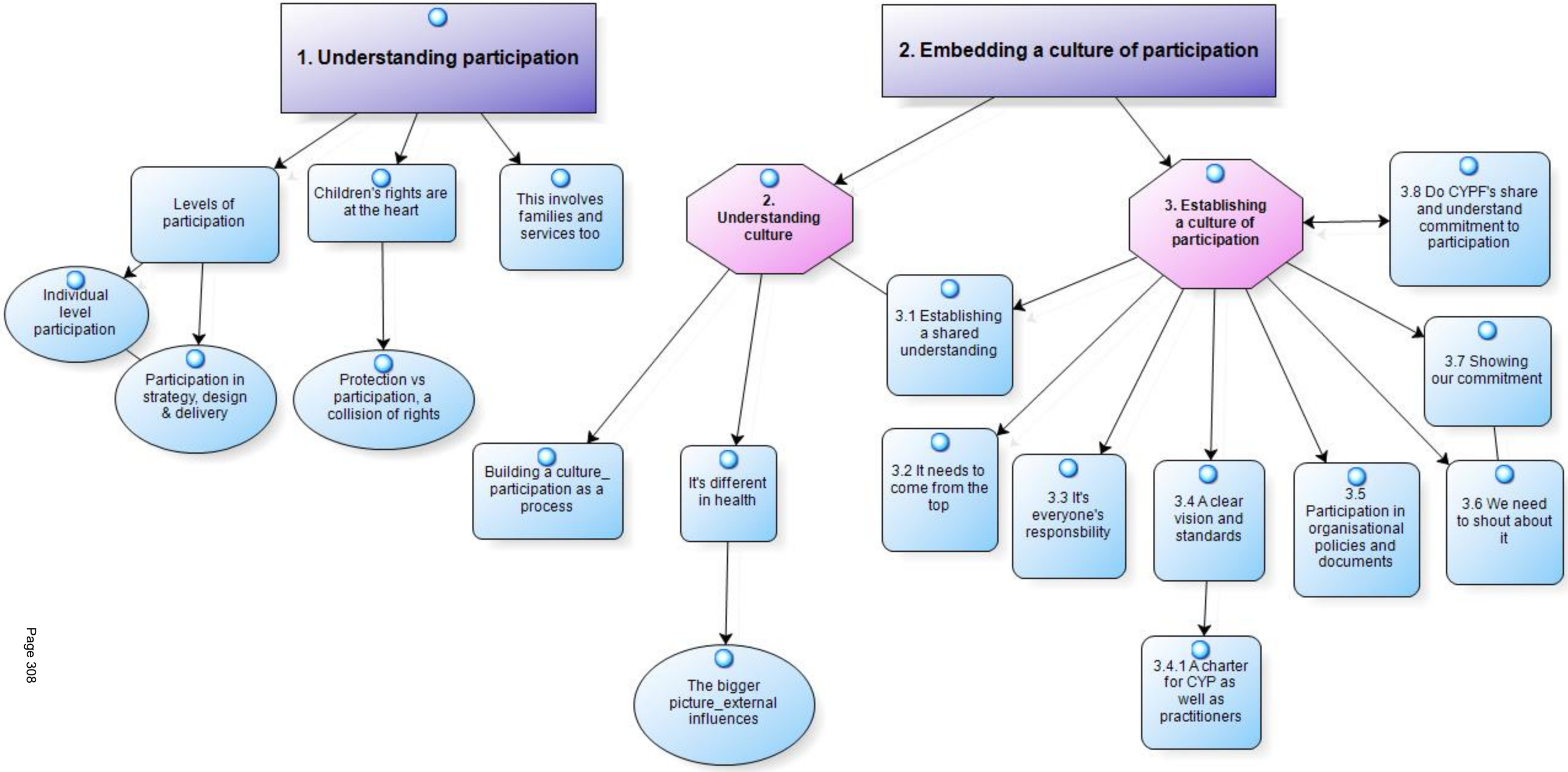
Source	Activities	Number of participants	Material generated for analysis
Young advisor meetings, September 2013 – November 2015	Small and large group discussions, creative activities	17 young people over 20 meetings	Meeting notes, newsletters for young people, flipcharts and photographs of creative outputs
Communication with young advisors in between meetings	Phone calls, emails, text messages, written responses to documents or queries	2	See 'activities', includes young people's contributions to study report
Trial management group meetings, June 2013 – Nov 2015	Discussions on 'public involvement' agenda items at 14 meetings	7-9 members of research team at each meeting	Meeting agendas, notes, documents (including updates and I colleague drafted for meetings on YP's involvement) and my own notes
Trial steering committee meetings	'Public involvement' agenda items at 2 meetings	N/A as analysis was of documentary material	Meeting agendas, notes and documents (including updates and I colleague drafted for meetings on YP's involvement
Project proposal, protocol and draft report	N/A	N/A	Used in documentary analysis
Study public involvement plans versions 1-4	N/A	N/A	Documentation of changing plans for YP's involvement
Meeting with young advisor B, Sept 2014	Discussion	Other public involvement lead, young person	Transcribed recording
Trial management group focus group, February 2015	Discussion around topic guide	6 members of TMG	Transcribed recording
Trial steering committee focus group, February 2015	Discussion around topic guide	3 members of TSC	Transcribed recording
Phone interview with young advisor A, October 2015	Discussion	Young person	Transcribed recording
Emails and journal entries	Correspondence, notes on meetings and my observations throughout the process	Various	Source of material to document process and my role in this

Appendix 15: Example thematic maps




2. FROM RHETORIC TO REALITY
2.1 Organisational processes
2.2 CYP's experience - what does good participation look like
A whole systems approach
2.1.1 Organisation - culture
2.1.2 Organisation - structure
2.1.3 Organisation - practice
2.1.4 Organisation - review
Participation as a lever for organisational change
Drawing from other models, tools and national work
External influences (policy, legislation, national drivers)
Involving all stakeholders
Building CYP's capacity to be involved
Enabling participation - working with parents, carers and families
Seeking to be inclusive and accessible
Tell me about my rights
Relevant to CYPs lives
Power and control
But it's not up to me' - power within and between organisations
We want it now'- building enthusiam for participation
Planning participation
Having the necessary resources
It's different in health'- embedding participation in the NHS
CYP's participation in CCHP service design and delivery
CYP's involvement in review
Review infrastructure- systems and processes needed
Communication - listening to staff as well as CYP
Communication - Raising the profile and keeping it there
Participation champions and expertise in practice
HYPE
It needs to come from the top' - governance and management
Participation in organisational policies and documents
Commitment by commissioners
There's so much going on' - mapping participation in complex organisations
Identifying gaps
CYP's participation as users of CCHP services
General principles but adaptable to needs of specific services
Recognising and sharing good practice
Sharing learning and celebrating success
Evidence of process - showing how and when participation happens
What difference did it make - Impact and outcomes of participation
Creating opportunities - working in ways that enable participation
Working together and making it real - Collaboration and shared learning
Collaboration _beyond health services
Implementing participation strategy and framework
Developing strategy and framework
Involving other stakeholders
YP's involvement in strategy


3. IT'S NOT STRAIGHTFORWARD
3.1 Gaps in understanding
3.2 Organisational barriers
3.3 Barriers for CYP
Medical & developmental vs social models of childhood
CYP as vulnerable (safeguarding vs rights)
Varied understanding, and appreciation of the importance of, participation
'Good enough' participation' - Being realistic but ambitious
Little acorns - Varied levels of participation practice
It's not that easy - hierarchy and structural barriers
Not another load of forms - Measuring but not monitorng
Short-term thinking - change and uncertainty
Things change so fast - internal
Things change so fast - external
What if they ask for things we can't do or change
Reinventing the wheel
I don't know where to start - confidence and expertise
Whose agenda
It's so difficult to be truly inclusive
Missed opportunities - who doesn't get involved
Its not for everyone - seldom heard or just not interested
'Some of this stuff can be really hard to understand'
Not just a one-off event
It's hard to say if I'm not happy
Personal circumstances or experience make participation difficult


1. Understanding participation
Levels of participation
Individual level participation
Participation in strategy, design & delivery
Children's rights are at the heart
Protection vs participation, a collision of rights
This involves families and services too
2. Embedding a culture of participation
2. Understanding culture
Building a culture_ participation as a process
It's different in health
The bigger picture_external influences
3. Establishing a culture of participation
3.1 Establishing a shared understanding
3.2 It needs to come from the top
3.3 It's everyone's responsbility
3.4 A clear vision and standards
3.4.1 A charter for CYP as well as practitioners
3.5 Participation in organisational policies and documents
3.6 We need to shout about it
3.7 Showing our commitment
3.8 Do CYPF's share and understand commitment to participation

Appendix 16: Final codes

1. Culture

Code name	Sources	Refs	Description
1. Understanding participation	2	2	How participation is defined and understood, in relation to how this shapes culture. Not process of defining which is 3.1
Children's rights are at the heart	4	14	Children's rights and UNCRC + child voice at the heart of a participation culture
Individual level participation	4	15	Understandings of participation as related to individual service-user experience (as opposed to practical examples of this in 2.1.3. Also need for 1:1 as well as group participation, eg in YSBNT
Participation in strategy, design & delivery	6	12	Understandings of participation as involvement in strategic & delivery and design decisions (but not practice examples - which should be in 2.1.3)
Protection vs participation, a collision of rights	9	21	Cultures, esp in health, of defining CYP as vulnerable + participation vs protection rights
This involves families and services too	6	18	Parents, carers and services as enablers and facilitators of CYP's participation
2. Understanding culture	8	22	Definitions and understandings of what is meant by 'culture of participation' - eg participation as part of the shared ethos of the organisation/project + why it's important to participation
Building a culture_ participation as a process	6	24	
It's different in health	9	32	Mentions of specific elements or aspects of health services & clinical research and how embedding participation in these settings/contexts may differ from non-health related settings
The bigger picture_external influences	11	48	Policy, legislation, national drivers + drawing from other tools and models
3. Establishing a culture of participation	0	0	
3.1 Establishing a shared understanding	10	41	Participation as a shared vision, understanding of participation as an activity, process and/or model;, values within organisation + how these are shaped, understanding current organisational culture & power structures. How participation is understood covered in 1, this is about process of establishing shared understanding
3.2 It needs to come from the top	7	16	Importance of managers (and commissioners) actively supporting and sustaining the development of participation. Need for management of change as well as

			redistribution of power, managers role in maintaining participation as a priority, ensuring adequate resourcing and addressing any resistance to change
3.3 It's everyone's responsibility	11	56	Ensuring that all staff are committed to participation, especially re: day-to-day contact with CYP (linked to 2.1). Need for participation to be bottom up as well as top down. Also issue of participation needing to be everybody's responsibility vs need for expertise and champions, building enthusiasm
3.4 A clear vision and standards	6	21	The need to develop a charter which sets out standards for participation on which practice will be based and progress can be measured. Need for this to be regularly reviewed and implications understood re: structure, practice and review
3.5 Participation in organisational policies and documents	7	17	Mention of participation having a role in organisational policies and other documents
3.6 We need to shout about it	7	25	Publicising commitment to participation: eg raising profile, sharing learning and celebrating success, promoting participation to CYP as well as staff
3.7 Showing our commitment	4	6	If and how demonstrate commitment to participation (eg communication)
3.8 Do CYPF's share and understand commitment to participation	10	42	

2. Structure

Code name	Sources	Refs	Description
1. Understanding structure	2	5	How structure is defined and understood. Consideration of the planning, decision-making processes and resources needed to develop participation within org/project
2. Why structure is important	11	59	How structures and infrastructure support the practice of participation & how poor participatory mechanisms create barriers.
Identifying gaps	2	5	Related to mapping - identifying and addressing gaps
3. Developing a participation strategy	9	68	Developing framework for setting outcomes and outlining process by which CYP will have the opportunity to participate (cross-ref with Culture 3.4)
Clear vision with flexbility	7	24	Balance between need for common standards & overarching principles vs something that has flexibility to be adapted to suit different services and service users
YP's involvement in strategy	5	46	Discussions about how YP were involved in the project, as opposed to their involvement in CCHP
4. Partnership working	5	15	Links to Culture 2: the bigger picture re: national initiatives + role of HYPE in CCHP & links w VCS orgs in Y-SBNT
HYPE	5	20	Barnardos HYPE staff, projects and role
Working together and	9	38	Shared learning within services, organisation and collaborating organisations (eg social care)

making it real - Collaboration and shared learning			
5. Participation champions	9	37	Specialist participation workers, staff & CYP as champions + may overlap w 4. re: role of VCS & see also Culture 3.2 re: management champions & 3.3 ' everybody's responsibility'
6. Providing adequate resources	8	31	Cost of ensuring participation is effectively developed, sustained and practiced. Need for specific budgets and l/t funding or integrated into org's way of working?

3. Practice

Code name	Sources	Refs	Description
1. Understanding practice	8	54	How people define working in ways which enable participation (eg developing the necessary skills, knowledge and experience)
2. Why practice is important	13	114	How the effective practice of participation creates positive change + how poor participatory practice creates obstacles to participation
Implementing CCHP participation strategy and framework	7	91	Discussions on putting strategy and framework into practice (as opposed to their development, discussed in 2.1.1)
Not an add-on	2	2	Participation is not an add-on (ie in opposition to embedded)
Not just ticking a box	3	4	
This isn't about consultation	1	3	Participation as being more than/different too participation
3. Involving all CYP	10	40	Inclusive practice. CYP are not a homogenous group. Issue of different levels of involvement for different groups
CYP's participation also involves families & services	3	7	Parents, carers and services as enablers and facilitators of CYP's participation. Importance of this to participation not practical examples
It should be fun	4	13	Participation as fun, enjoyable, creative
4. Ensuring safe participation	11	29	Issues of consent, protection, access, reward & recognition
5. Creating a CYP-friendly environment	10	20	Creating an accessible and welcoming environment - physical surroundings & adult attitudes
5.1. Using creative and flexible approaches	10	33	Adapting adult-orientated decision-making processes so tthat they are more accessible for CYP
Fitting participation to	3	13	CYP-centered participatiom

CYP not CYP to participation			
6. Mechanisms and models for involving CYP	9	19	Incl consultation & YPAGs + see also Culture 1. levels of participation & 3.4.1 a charter for CYP + involvement of YP in organisational practice eg training, recruitment, promotion & dissemination
Enabling participation - working with parents, carers and families	8	67	Examples of working with parents and families in practice
Enabling participation - working with services	4	15	Especially re: role of services in YSBNT
7. Competencies required for participation	8	18	Key competencies required by adults and CYP to implement and enable meaningful participation
We are the experts in being young people	7	13	Ideas of CYP being 'experts by experience'/ having expertise, knowledge and perspectives that adults do not have

4. Review

1. Why the review process is important	2	2	
Sharing learning and celebrating success	6	21	How learning and data on impact and outcomes related to participation is shared within and outside the organisation
2. Developing review systems	0	0	Incl identifying outcomes
2.1 Involving CYP in reviewing participation	3	3	
2.2 Resourcing review systems	2	7	
2.3 Evidencing the process of participation	9	45	
2.4 Reviewing outcomes of participation	8	29	