

Guidelines for Research with Children and Young People

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NCB's vision is a society in which children and young people are valued, their rights respected and their responsibilities enhanced.

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Contents

1. Introduction	3
2. Research with CYP: Overview	4
2.1 CYP's participation at NCB	4
2.2 Principles, values and benefits of involving CYP	4
2.3 How we involve CYP in research at NCB	6
2.4 Models of involvement in practice.....	9
3. CYP as research participants	13
3.1 Practicalities	13
3.2 Accessibility and inclusion	16
3.3 Methodological issues	20
3.3.1 <i>Quantitative research with CYP</i>	20
3.3.2 <i>Qualitative research with CYP</i>	21
3.3.3 <i>Research involving observation of CYP</i>	26
3.4 Ethics.....	27
3.4.1 <i>Consent</i>	27
3.4.2 <i>Confidentiality, child protection and safeguarding</i>	33
4. Involving CYP in research	35
4.1 Planning to involve CYP	35
4.1.1 <i>Initial considerations</i>	35
4.1.2 <i>Resourcing</i>	36
4.1.3 <i>Practicalities</i>	37
4.1.4 <i>Policies and procedures</i>	39
4.1.5 <i>Induction, training and support</i>	41
4.1.6 <i>Reward and recognition</i>	42
4.2 Ethics.....	43
4.2.1 <i>Informed consent</i>	43
4.2.2 <i>Child protection and safeguarding</i>	43
4.3 Involving CYP in stages of the research process	44
4.3.1 <i>Proposal writing and research design</i>	44
4.3.2 <i>Advisory groups</i>	44
4.3.3 <i>Developing research tools</i>	46
4.3.4 <i>Recruitment of research participants</i>	47
4.3.5 <i>Data collection</i>	48
4.3.6 <i>Data analysis and interpretation</i>	49
4.3.7 <i>Reporting research findings</i>	51
4.3.8 <i>Dissemination</i>	54
5. Review and evaluation	56
5.1 End of project review	56
5.2 More formal evaluation of CYP's involvement in research	56

1. Introduction

These guidelines have been produced for researchers who are contemplating involving children and young people (CYP) in their research project – whether as participants or in a more active role.

These guidelines:

- set out NCB Research Centre's general approach to research with CYP (Section 2)
- provide practical guidance for the researcher, through all stages of the research process from planning to dissemination:
 - o Section 3 focuses on research in which CYP are participants (that is, as sources of data)
 - o Section 4 considers other ways in which CYP can be involved in the research process
- are illustrated throughout with examples from the recent work of NCB's Research Centre.

A note on language used in these guidelines

*The acronym **CYP** stands for 'children and young people'. For the sake of brevity, in these guidelines the word **child** is used to refer to an individual child or young person.*

*Similarly **research** should be taken to encompass all forms of research, including evaluation.*

*The terms 'involvement' and 'participation' are often used interchangeably, which can lead to confusion, particularly in a research context where the term 'participants' generally refers to research subjects. In these guidelines, for the sake of clarity the term **participation** is only used in situations when CYP are research subjects (sources of data), whereas **involvement** is used to describe situations in which CYP are active partners in the research process itself.*

2. Research with CYP: Overview

This introductory section provides context and a general overview of principles. It outlines the policy and practice background to the involvement of CYP in research and the benefits of doing so, including specific examples from the NCB Research Centre's work.

2.1 CYP's participation at NCB

The involvement of CYP in research needs to be placed within the context of an international rights-based framework within which CYP were granted a right to have a say. Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) states that all CYP who are capable of forming their own views, have a right to express those views freely in all matters affecting them, with the views of the child being given due weight in accordance with their age and maturity.

NCB defines participation as 'the means, by which CYP influence decisions that bring about change in them, others, their services and their communities'. Recognising that CYP are experts in their own lives is vital to ensuring that the voices of CYP, including those from vulnerable backgrounds aged up to 18 (and up to 25 for those in public care or with learning difficulties), influence research, policy and practice, and inform service developments.

2.2 Principles, values and benefits of involving CYP

In conventional research methodologies CYP (like other frequently researched groups) were often excluded from the process of shaping the research agenda or the scope of specific research projects, their perspectives being filtered through the interpretations of adult researchers. In recent years there has been a theoretical and methodological shift within social research: away from traditional approaches which saw CYP solely as objects of enquiry, and towards a view that CYP are social actors with a unique perspective and insight into their own reality.

In participatory research, both researchers and those researched are recognised as active participants in the research process. This approach to research also seeks to address some of the power imbalances between the researcher and the researched, which can be compounded for CYP by the adult-child dynamic.

These guidelines are based on the premise that CYP are social actors who have a right to be involved in research about issues of concern to them. It is important to note that we not only seek to involve CYP in research because they have a right to be involved but also to improve the quality of the research itself. A recent review, *Exploring Impact: Public involvement in NHS, public health and social care research* (Staley 2009), found that public involvement in research improved recruitment, the quality and robustness of data and its interpretation, and the communication of findings. The review found that

involvement was perceived as making research more relevant and therefore more persuasive for policymakers and practitioners.

It may be necessary to argue the case for involving CYP, if faced with a participation-sceptic or a dubious funder, so a number of these are outlined below.

Benefits to the research process and validity

Involving CYP in research can benefit the research by:

- keeping it grounded in the lived experience of CYP, ensuring that researchers stay mindful of young people's perspectives throughout the process
- supporting recruitment of young research participants (and so boosting response rates). For example, involving CYP can:
 - o facilitate access to potential research participants
 - o ensure information and recruitment materials are accessible and relevant to their peers
 - o enhance the credibility of the study for other CYP
- helping to identify appropriate methodologies, or creative and innovative ways of collecting data, that are acceptable to their peers
- ensuring that research tools are relevant (for example, questionnaires and interview schedules) and issues are approached using language they understand
- enhancing the quality and quantity of data gathered – for example, if CYP are involved in conducting interviews, they may put their peers at ease more readily than adult researchers
- bringing an additional perspective to the interpretation of research findings.

Benefits for the communication of research findings

Involving CYP in research can be beneficial to its dissemination by:

- ensuring that the findings are accessible to other CYP, raising awareness of issues which affect them
- enabling young people to share their own related experiences, which can have a powerful impact on audiences of all ages.

Benefits for CYP involved in research

Involving CYP in research gives them an opportunity to:

- access their right to have a say in decisions that affect their lives
- make an active contribution to their communities and to improve services used by CYP
- develop a variety of transferable skills (for example, in research, presentation, project management, negotiation and decision-making)
- develop and extend their social skills and networks, through working with both adults and peers

- access broader personal development, for example increased confidence, knowledge, self-esteem, and the confirmation that their views matter and can effect change
- enhance their CV
- gain acknowledgement of their contribution by receiving a payment, reward or other recognition (see Section 4.1.6 Reward and recognition).

Potential wider benefits

- Research involving CYP, if used to inform decision-making or policy formation, is likely to lead to policies and services that reflect CYP's priorities and concerns.
- The research can offer practitioners new ways of engaging with CYP, highlighting existing or newly acquired skills and competencies, and leading to greater mutual understanding and respect.
- In organisations where this is not already developed, involving CYP in research can help to promote a more participative culture.

2.3 How we involve CYP in research at NCB

At NCB we recognise that CYP are experts in their own lives. By involving them, whenever possible, in the planning and process of research, we can ensure that their views and experiences are taken into account in what is researched, how the research is conducted and how the findings are disseminated and used.

NCB Research Centre objectives for involving CYP are to:

- ensure that our activity meaningfully involves CYP, at both strategic and project level, and seeks to identify and remove any barriers to doing so wherever possible
- support CYP's involvement in research projects across the spectrum, from research participants to projects in which CYP have ownership of the research
- recruit, train, support and reward CYP appropriately and ensure that adequate staff capacity to support this work is taken into account at the costing stage of all proposals
- ensure that all involvement of CYP is evidence-based, ethical, realistic and properly resourced
- give feedback on any findings on the benefits of CYP's involvement in research to the individuals involved, internally and to the project funder to develop and disseminate good practice.

Figure 1 illustrates the different ways in which CYP may be involved in research activities. We do not take the view that one or other form of involvement is inherently 'better' than another; rather, the approach taken will be determined according to the nature of the specific research project or activity, the available resources and the preferences of the CYP concerned.

The figure illustrates a clear distinction¹ between CYP being research participants (the single circle on the left) and their involvement in the planning and process of the research itself (the overlapping circles on the right). The three interlinked circles in Figure 1 illustrate the varying degrees of control that CYP may have in the planning and process of research. The circles are represented as overlapping (and porous), reflecting the fact that – within a single project – the nature of involvement may vary for different CYP, or at different stages of the research process (see Section 2.4).

Figure 1: Models of CYP's involvement in research

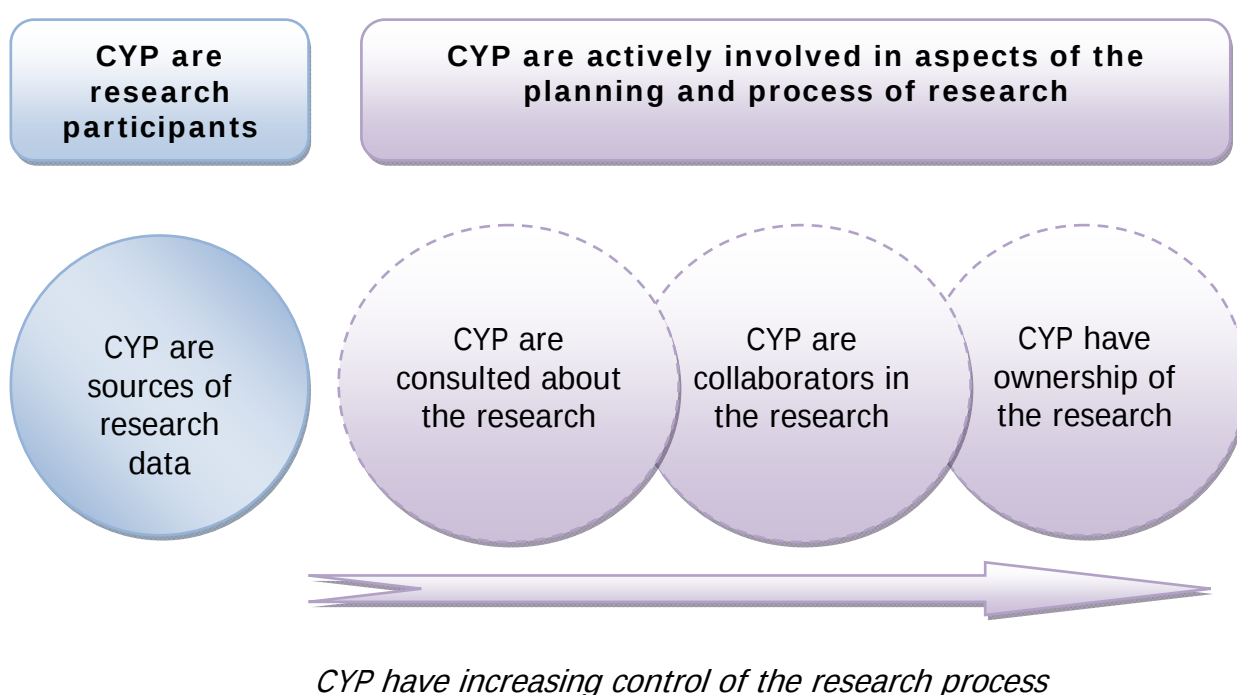


Table 1 (overleaf) sets out the distinguishing features of each of the models, and the implications for the roles of both adults and CYP.

¹ While some studies may involve CYP in both the research process *and* as participants, these would generally be two discrete groups of CYP, i.e. those CYP actively involved in the research process would not themselves be sources of data.

Table 1: Features of the different models of involvement

Models of involvement	CYP are sources of research data	CYP are consulted about the research	CYP are collaborators in the research	CYP have ownership of the research
Aspects of CYP's role				
Decision-making	Adults in control of all decisions (although individual CYP can decide whether or not to take part)	Adults take CYP's views into account when making decisions	Decision-making shared, or negotiated, between adults and CYP	Adults provide advice and guidance to CYP and support them to make informed decisions
Developing research idea or proposal, designing and planning research	No involvement (unless participating in pilot study)	CYP may be consulted during development stage	CYP and adults may develop and plan research together	CYP initiate research idea and have major influence on design and methodology
Duration of involvement with the research	At data collection points only	CYP's involvement likely to be sporadic (at key decision-making points)	CYP potentially involved at any or all stages of research	CYP likely to be involved throughout: from conception to dissemination
Research participants, providing data	Yes	No	No	No
Involvement in collection and analysis of data	No	Unlikely, though may be consulted on tools or interpretation of findings	May be actively involved in some aspects (e.g. designing tools, data gathering, interpretation)	CYP potentially involved in all aspects of the research process (if they wish)
Reporting / dissemination	No involvement. However, findings of research should be fed back to participants if possible	May be asked to comment on draft report or dissemination plans	CYP may have role in report-writing (e.g. for CYP audience) and contribute to dissemination activities	CYP may take lead in some reporting and dissemination activities

Please note that NCB does not advocate a model of involvement that gives CYP *total* control over the research process, as we believe that this could potentially undermine the quality of the research and/or result in unethical or illegal practices.

2.4 Models of involvement in practice

The following explains further how the different models work in practice and the implications of working with CYP in each of these ways. Practice examples illustrate the interlinked and overlapping nature of the categories.

CYP are sources of research data (research participants)

In this 'conventional research' model, CYP are involved solely as research participants, that is, data is collected from them – by adult researchers – in the form of views, experiences, attitudes, expectations, observations and so on. This is their only involvement in the research process. However, wherever possible, research findings should be shared with participants.

Case Study 1:

Children's input into decision-making in different settings

NCB and the Children's Rights Alliance for England (CRAE), in research carried out for the National Participation Forum, conducted 12 focus-group interviews with 86 children aged 3–20 years old living throughout England. The aim of this research was to examine whether and to what extent CYP felt they had a voice or influence on decisions affecting their lives in various settings such as the home, school and their local area.

Participating in a focus group interview was the only way in which CYP contributed to this research, as budget and time constraints meant it was not possible to involve them in other ways. Thus, even though the *subject* of the research was participation, the research itself was not participative.

CYP are consulted about the research

In this model, CYP are actively and directly consulted at key decision points in the planning and process of research. This may be on an ad hoc basis (for example, if consultation groups are convened for specific purposes) or an ongoing basis (for example, as members of a standing advisory or reference group that meets regularly throughout the research project). Through this, they are given the opportunity to share their views and discuss issues with the research team on what is being researched and how. Their views will be taken into account by adult researchers, alongside those of other stakeholders. It is important that CYP are made aware of the limits of their influence. While adult researchers hold ultimate responsibility for decision-making, the rationale for key decisions should be clearly explained to the CYP involved.

Case Study 2:

Investigation into Children's Rights

In the 2008 Get Ready for Geneva project run by CRAE, a group of CYP, were supported to design and carry out their own 'Children's Rights' investigation. They were to see what progress the UK government had made towards addressing the 2002 concluding observations of the UN Committee on the Rights of the Child. CYP undertook various roles in this project, including sitting on the project's steering group; being members of a web and communication team; and being Children's Rights investigators. With support from the project team, CYP helped design the data collection tools, conduct fieldwork, analyse the findings and write a report. This they presented to the UN Committee on the Rights of the Child to help inform the examination of the UK government's implementation of the UNCRC.

Although the remit of the project was framed within an adult perspective (as the point of the examination process was to measure how far the UK government had addressed the concerns that the Committee had raised in their previous periodic report), CYP were involved in all stages of planning and carrying out the research, thus ensuring that the process and findings remained grounded in their views and experiences. This is a good example of how different models of involvement can be deployed within a single project. While children were 'consulted', in that they were represented alongside adults on the steering group, they also had a significant collaborative role when it came to carrying out the research and presenting the findings.

CYP are collaborators in the research

It is likely that such a project will include specific objectives to promote and support CYP's involvement in research. Thus CYP's involvement is assumed from the outset and enshrined in the project proposal and other documentation. There should therefore be an explicitly stated commitment for researchers to seek input from, and undertake joint decision-making with, CYP (who may be members of an advisory group and/or young researchers) at agreed key points of the research through negotiation, consensus or voting. The main tangible difference between this and the consultative model is that there is greater scope for CYP to influence the research, and more opportunities for their ongoing and active involvement. Each individual child or young person should be able to decide for themselves which of these opportunities they take up.

Adult researchers still hold ultimate responsibility for maintaining quality standards and leading on technical aspects of the research, as well as on ethical and legal issues. Again the limits of CYP's involvement and influence should be agreed with them at the outset and revised as appropriate.

Case Study 3:

PEAR: CYP's involvement in public health research

The PEAR project was funded specifically to promote CYP's involvement in and engagement with public health research. It was not in itself a 'research project'. Although the overall project structure and broad objectives were defined in the project proposal (itself developed with input from young people involved in a pilot group), within these broad parameters there was a lot of scope for group members to decide the form that the project took. The group was also provided with a budget that could be spent as they chose; they decided that they wanted to commission a research project. Group members decided on the topic, helped to draft a project specification and were involved in the research process. The group has been consulted by a number of public health researchers about various aspects of their own projects. Group members have also contributed to the design and content of the PEAR website and were actively involved in the planning and administration of the project conference, including making presentations and running workshops. See www.ncb.org.uk/PEAR for more information.

Again, the PEAR project demonstrates a range of different models of involvement, including consultation (in relation to other research projects), collaboration (in shaping the PEAR project as a whole), and ownership (in terms of commissioning a research project, with adult support).

CYP have ownership of the research

Peer or young people-led research gives CYP greatest control over 'their' research project and they may have responsibility for all aspects of a project from developing research questions or hypotheses and overall research design, to data collection, analysis, reporting and dissemination.

However, it must also be acknowledged that CYP will not have the skills or expertise of professional researchers so will still require ongoing training and support from adult researchers. This is likely to include advice and guidance on different approaches and their implications, enabling CYP to make informed and ethical choices about methodology and the deployment of resources. Adult researchers may undertake some of the work with or on behalf of the CYP, with their agreement.

While this model may place greater emphasis and importance on the participation, empowerment and personal development of the CYP involved, it is NCB's view that this should not be allowed to override considerations of ethics or research quality. Adult researchers will still need to hold ultimate responsibility for ensuring that the research is of the highest possible quality under the circumstances, and that ethical guidelines are adhered to. If adult researchers have any concerns of an ethical, legal or methodological nature, they will need to be clearly explained to the CYP, and a solution negotiated.

It should also be recognised that not all CYP involved in a project may want to be involved at all stages, and that in any group some may be less actively

involved than others. Their wishes should be respected, and should not detract from the CYP's overall ownership of the project.

Case Study 4:

Young people-led research

The Young Researcher Network promotes and supports young people-led research. As part of the network, NCB recruited a group of young researchers who decided on a research topic (the portrayal of teenagers in the media), designed a methodology, undertook data collection (survey and focus groups) and contributed to data analysis, report-writing and dissemination. The group received training and support for each stage of the research, and decided to delegate some elements of the project to the adults supporting them (the literature review, completing and overseeing data analysis, and report writing). At the outset it was agreed that adult researchers would have ultimate responsibility for technical, ethical and legal aspects of the research as well as budget management, but group members were involved in or informed about all key decisions.

This is a fairly clear-cut example of children owning a research project from conception to dissemination.

3. CYP as research participants

NCB Research Centre takes the view that neither research design nor methodology should be compromised because CYP are to be involved as research participants. Rather, the choice of research method should be guided primarily by the research objectives and modified, where necessary, to reflect ethical or practical considerations. The challenge for the researcher is to ensure that the process is enjoyable, acceptable and appropriate for participants, while at the same time maximising the robustness and utility of the data collected.

This section offers guidance on practical, methodological and ethical issues associated with conducting research with CYP. It is assumed that at this stage, the overall objectives for any research project will have been formulated.

3.1 Practicalities

The following issues are relevant to all research with CYP, regardless of methodology.

Access and gatekeepers

Recruiting CYP to take part in research can be a very time-consuming process due to the need to work with gatekeepers to gain access to CYP within settings, plus additional time for obtaining consent from parents and carers (for CYP under 16).

It will generally be necessary to obtain the permission² of the manager of the setting (for example, headteacher or equivalent) to undertake the research in the first instance and they will need to be provided with written information about what is proposed. In particular they are likely to want reassurance that the research is of value/interest; will be conducted safely and ethically; and will place a minimal burden on their staff and participants. In support of this, they may ask for additional documentation (for example, copies of CRB checks or organisational policies) and may also need to seek additional clearance from their senior management.

Occasionally, this type of negotiation may require senior-level input and sometimes lengthy discussions to secure buy-in, particularly where there is potential conflict between a setting manager's requirements and what is appropriate in research, time or budgetary terms. For example, access to setting-specific data is often requested but is not always appropriate.

In our experience, it is good practice to appoint a designated contact person in the research team to manage day-to-day liaison with the setting. It can be time consuming to deal with the various practicalities, such as acquiring sample data; ensuring information sheets and consent forms are distributed to

² NB this does not constitute 'consent' on behalf of any or all potential research participants.

CYP (and parents if appropriate); and helping to set up data-collection processes. You will also need to agree child protection procedures.

While we often require the cooperation of gatekeepers, they should not be the final decision-makers on who should and should not be invited to participate in the research. Often, through a desire to be 'helpful', gatekeepers will put forward potential participants who they believe may be most confident or forthcoming, or who they believe have the most interesting (or, in the case of evaluation, positive) stories to tell. It is important to tactfully resist assistance of this sort.

Recruitment of CYP may also be done directly via parents. Here, the parent is not only a 'gatekeeper' to be persuaded of the value of the research, but is also – if the child is under 16 – usually required to give consent for their child to take part (for more on parental consent see Ethics, Section 3.4.2).

Sometimes gatekeepers (including parents and carers) ask if they can sit in during the collection of data. In certain circumstances this is appropriate, or even necessary, for example:

- if a disabled child has particular communication or support needs
- if a child specifically requests that a parent or carer (or other) is present
- when administering a questionnaire to a class of children (teachers or teaching assistants can help to maintain discipline within the group as well as providing support to individuals if required).

However, in such situations, gatekeepers and parents need to be carefully briefed on the neutrality of their role and understand that they should not attempt to influence or interpret the responses of participants.

In other situations, the presence of gatekeepers is not appropriate and should be discouraged as it could potentially introduce serious bias to the data. For example:

- in a one-to-one interview situation a child could be inhibited about revealing personal information or feel obliged to provide socially acceptable responses
- if members of staff are present during interviews or focus groups to discuss a particular project or service that they have some responsibility for (for example, as part of an evaluation), CYP may feel unable to offer critical comments.

The research location and environment

It is important to consider the effect that the data collection environment may have on the responses of CYP taking part in research. For example, if conducting an interview of a small focus group in a large boardroom, the sheer size and formality of the setting may be inhibiting. If school is the setting, be aware of CYP's usual experiences in this environment (for example, pressure to only provide the 'right' answers, adults being the experts). Evaluation interviews taking place in the same setting as the service or project is delivered may lead to confusion between the evaluation process and service delivery.

While you may not be able to control the environment, or offer an appropriate alternative, it is wise to at least be aware of its potential effect and do what you can to minimise the impact on the research.

Power issues

It is also important to recognise the natural power imbalance between adult (researcher) and child (participant), and the effect that this is likely to have on the data collected. While it can never be entirely eliminated, various steps can be taken to minimise the impact, including:

- creating a relaxed atmosphere prior to embarking on the data collection proper, which could mean having an informal chat at the beginning of an interview or warm-up activities at the start of a focus group
- ensuring that participants understand that data collection processes are not 'tests' in any sense, and that all responses are equally acceptable, valid and welcomed
- dressing informally (without trying to be 'down with the kids')
- avoiding formal seating or room layout, for instance by not sitting behind a desk and, if possible, literally coming down to the level of the child.

Giving feedback to participants on the findings

It is good practice to ensure that research findings are fed back to participants, including any CYP involved. NCB recommends that:

- you have some means of communicating findings with those who wish to receive them (for example, during the research process you collect the contact details of those who express an interest in the findings)
- the findings are accessible and specifically tailored to the CYP in question (that is, probably not just a copy of the executive summary)
- an appropriate format is used – for older CYP you may want to produce a young person's version of some of the key findings (something that young researchers or advisors may be involved in drafting), on other occasions an online video clip, poster or feedback event may be more appropriate
- you think carefully about which findings are likely to be of greatest interest to this audience, and highlight these
- you include information on what will happen next (for example, 'we will now be making recommendations to the government that...' or 'NCB will now use the research to help improve services for CYP by...').

Dissemination

In addition to making research findings available to research participants (above), it is important to recognise that CYP (and subgroups of CYP) can be important stakeholders more generally. Thus they should be considered a potential audience for wider attempts to disseminate the findings to policymakers, practitioners, funders and so on.

The channels for this might include:

- those organisations involved in the research process, for example by having recruited research participants

- press releases to CYP's news media (for example, CBBC's *Newsround*)
- Young NCB's magazine (*Loudspeaker*) or the Young NCB website.

3.2 Accessibility and inclusion

Involving CYP as participants in research involves particular methodological challenges. The choice of research method must be appropriate for the aims of the study, manageable within the time and budget constraints, yet also be meaningful and accessible for the CYP in question.

Sampling: Diversity and inclusion

The UN Committee on the Rights of the Child has identified a number of groups of CYP as being amongst the least likely to be able to access their rights. These groups include those who are:

- very young
- young parents
- 16–18 year olds
- black and minority ethnic
- disabled
- in public care
- refugees and asylum seekers
- in trouble with the law
- living in poverty
- affected by violence, abuse and neglect
- lesbian, gay, bisexual and transgender
- Travellers.

It is important to ensure your chosen method or sampling strategy does not systematically exclude CYP from these (or other) groups from participating in the research. For example, using schools to access CYP means that those not in mainstream education (for example, those who are home educated, in secure institutions or persistent truants) will be excluded from participating.

There may be resource implications involved. For example, if your sample is known to contain CYP who have English as an additional language you will need to consider the use of interpreters or translators. If the budget doesn't stretch to this, you will need to acknowledge that this group of CYP has been excluded from the research, and discuss the implications of this in relation to the findings.

The age of participants

The age of children you wish to include in the research will have a significant impact on the method you choose and the design of research tools.

For CYP of **secondary school** age, most methods that would be used with adults can be considered – for example, self-completion questionnaires, one-to-one interviews and focus groups. However, a degree of adaptation to the age group will be required in order to reflect their level of literacy, cognitive ability and capacity to understand abstract concepts.

For children of **primary school** age, very formal or structured methods are less appropriate.

It is particularly important that all tools (for example, questionnaires or interview schedules) are piloted with CYP of the same age as your potential participants to ensure that the language is appropriate and the length acceptable.

There is no lower age limit at which CYP can participate in research, assuming the methodology is appropriate to the age group in question. When conducting research with **very young children** (under fives), you need to consider:

- how to couch the aims of the research in a language the children can understand, and gain the informed consent of the child (primarily an ethical issue)
- young children's level of understanding and what they can meaningfully contribute to the research
- the need to employ a multi-method approach, so that data gathered from very young children can be supplemented and contextualised with data gathered by adults (particularly those who know the child well)
- using a range of creative methods
- the short attention span of very young children and the likely need to schedule several short data collection sessions, rather than a single visit. This will have implications for the planning of fieldwork.

When working with very young children, you will find that the practitioners (for example in early years settings) and parents (for example in home settings) can play an important role in ensuring the child is comfortable and understands the research process. They can also help the child and researcher communicate more effectively, since the child's language might not be sufficiently well-developed to be understandable to the researcher. A balancing act is often required, however, to ensure that the involvement of 'intermediaries' does not overly influence or submerge efforts to elicit the child's perspective.

For more specific guidance on using different research methods with CYP, see Section 3.3.

CYP with specific needs or vulnerabilities

In order to develop appropriate approaches to engage in research those CYP with particular needs or identified as 'vulnerable', it is particularly useful to consult with practitioners and gatekeepers who know them well. Where relevant, we also recommend briefly reviewing any recent research among similar groups of CYP to see how other researchers have engaged with them, and the challenges they faced.

For example, it has been noted that young refugees and asylum seekers may be uncomfortable with the use of digital voice recorders in the research process because it can remind them of their experiences in detention or immigration centres. In a situation such as this, it would be important to raise this issue with the gatekeeper in advance of the interview to ascertain what would be an appropriate and acceptable way to proceed.

When disabled CYP are research participants, it is important that creative, multi-method, flexible approaches are adopted, which can be tailored to the needs of those involved. It is particularly important to note that within any group of disabled CYP, there is likely to be a range of needs and abilities, therefore tools may need to be adapted to suit the individuals not the group as a whole. Again, such decisions will be informed by consulting relevant experts (for example, parents, practitioners and support workers) and it may well be necessary to work alongside support staff or interpreters when undertaking data collection.

The Council for Disabled Children and other disability charities may be able to offer additional advice and guidance in this respect.

Case Study 5:

National Participation Forum

The National Participation Forum's review into CYP's involvement in participation examined whether and in what settings children feel they have a voice and influence over decisions affecting them. NCB and CRAE conducted 12 focus groups with children aged 3–20 years living in different circumstances. While the research questions remained constant, each focus group was approached differently to accommodate the abilities, experiences and needs of group members. Some examples of this are given below.

For the focus groups conducted with children at **primary school**, NCB produced three different collages of pictures representing different types of decisions children might be involved in: 1) at school, 2) in the home, 3) in their community. For example, collage '1' showed many images including children eating in a canteen, studying in the classroom, interviewing teachers for a new job, playing in the playground, designing a school uniform, and a child being taught at home. Children of different gender, age, ethnic background, and ability or disability were depicted but, as far as possible, generic images were chosen to encourage children to comment on the core objective of 'decision-making'.

Focus groups conducted with **children aged 3–4** were led by a practitioner with whom the children were familiar. For these interviews, four key questions were identified from the main topic guide. These were each written onto an A4 card, then age-appropriate symbols and characters with which the children were familiar were used to encourage them to engage in the discussion.

To assist with one group of **disabled children** aged 4–13 years with a diverse range of physical and mental disabilities, child mentors (or 'buddies') were enlisted to offer support to a younger disabled child. Buddies were briefed on the aims of the research in advance; and the research team worked with them to rephrase the questions in a way that participants would understand. During the session, buddies asked the questions and the researchers recorded the answers.

Children with severe learning impairments were engaged via adult support workers who were attuned to their individual communication needs. The adults asked each child to point to the picture that best represented their response to a particular question, then recorded this information along with any additional comments from the child.

Groups of children with **particular experiences** (such as young carers, Travellers, and asylum seekers), were asked additional questions relevant to their specific circumstances.

3.3 Methodological issues

It is not the intention of these guidelines to offer detailed information on good research practice, as this is widely available in other publications and online. Instead, this section focuses specifically on methodological issues relating to CYP as research participants. That said, there are some general points to make about conducting research, which are of universal importance, and these are summarised below.

- keep data collection brief and to the point; and bear in mind that CYP have shorter attention spans than adults
- aim to create an open and informal atmosphere
- stress the point that there are no right or wrong answers (and reiterate this message during data collection as appropriate)
- use short questions and simple language, avoiding abstract concepts wherever possible
- do not assume that a respondent will interpret the question or a response in the way it is intended. For example, a response of '*I don't know*' may be interpreted as '*I don't know what you are talking about*' – so it is important to keep checking what you think the respondent means with what they *actually* mean
- ensure that tools are accessible (in terms of length, format, content, language), given the age and cognition of the sample in question
- it may be necessary to produce different versions of the tool for different age and ability groups
- thorough piloting is essential.

3.3.1 Quantitative research with CYP

Gathering quantitative data from CYP may involve self-completion questionnaires (on paper, on a computer or via the web); the administration of standardised tests or measures; structured interviews (face-to-face or by telephone); or observation.

A note on the use of self-completion questionnaires

We do not recommend using self-completion questionnaires with children under the age of 12, *unless* an appropriate level of support is available (for example, in a classroom setting with several researchers or helpers available to assist) to ensure that individual children, and particularly those with learning difficulties, are not left out or negatively impacted by the process. In such circumstances, we would expect a researcher to lead the data collection process rather than hand over responsibility entirely to a class teacher or other gatekeeper.

Similarly, NCB does not advocate the use of web-surveys for children under the age of 12, particularly those that are 'open access' on websites, as opposed to those emailed to individuals. In addition to some of the general limitations of web-based research among children, such as obtaining parental consent (see 3.4.1 below), unlike in a classroom setting the extent to which

young children can appropriately read, understand and meaningfully respond to individual questions is largely unknown. While for large sample sizes the impact of poor quality responses from some respondents may be mitigated, the reliability of any findings may be questionable for small sample sizes. Web-based surveys should certainly not be used if the research is potentially controversial, or the subject matter at all sensitive.

See Section 3.3.3 for guidance on carrying out structured observations of children.

3.3.2 Qualitative research with CYP

Carrying out qualitative research with CYP is largely a matter of following good qualitative practices in general. These include:

- having clearly defined research objectives, that are of relevance and importance to the participants
- using a well-designed topic guide that has been piloted among several CYP of a similar age
- ensuring discussion takes places in a non-threatening, comfortable setting
- having the facilitator create a relaxed and open atmosphere where all participants are encouraged to share their views
- actively listening and being sensitive to the impact of the process on the interviewee.

Individual qualitative interviews

When addressing very sensitive or traumatic issues in interviews with CYP, it may be useful to de-personalise questions or provide scenarios as a prompt for discussion. Sometimes props can be useful (for example, asking the child to give advice to a doll or a puppet). Posing questions in the third person can also avoid the risk of CYP looking for a 'right' answer or feeling threatened by direct questioning. However, for some studies it may be necessary to ask CYP directly about their own experiences, in which case this needs to be approached sensitively. Some CYP may prefer to express their thoughts and feelings through drawing, though in such cases it is essential to ask the child to explain what they have produced.

Paired or triad interviews

To mitigate some of the power imbalance when adults are interviewing CYP, it can be beneficial to conduct paired (or triad) interviews with CYP who already know each other well. CYP are likely to, more readily, feel less intimidated in such a situation, and be open and honest in their responses (and encourage each other to do so). However, it is important to consider the subject of the research as it may not be suitable if you need to collect detailed or sensitive information at an individual level. In such a case, the research design would ideally be flexible enough to ask respondents at the recruitment stage whether they would be happy to be interviewed on their own or with a friend.

Focus groups

Some key principles when planning focus groups with CYP are as follows.

- Groups for CYP and young people should generally be smaller than for adult participants (6–8 participants is optimum).
- Joining a group of strangers is daunting for most CYP, so consider recruiting them in friendship pairs if participants do not already know each other.
- Avoid having too wide an age range within a single group (for example, keep it to less than 2 or 3 years), as it will be difficult to pitch the discussion at a level that is accessible and interesting for all participants.
- At certain ages, CYP are more comfortable talking in single-sex groups; it is best to take advice from gatekeepers as to whether mixed or single-sex groups would work best with the age group in question.
- Avoid using a dry 'question and answer' format for the entire session; include some more interactive and creative activities.
- Use ice-breaking exercises before launching into data collection, and to re-energise if necessary.
- A focus group for CYP should not last too long (certainly no longer than 90 minutes).

Setting focus group ground rules

CYP cannot be expected to be familiar with the etiquette of group discussions, so it is important to agree ground rules at the start. This can be done in a brainstorming session, followed by a discussion of the suggested ideas. Researchers should ensure all important points are included. Key to these rules will be the importance of: enabling individuals to make their points without being interrupted; listening and respecting other people's views; not shouting or swearing; and allowing one person to speak at a time.

Ice-breakers

The purpose of starting a session with an ice-breaker is to:

- make CYP feel relaxed and comfortable before starting data collection
- help CYP get to know one another
- allow participants to 'find their voice' in the group setting
- help the researcher get to know the group, and the different personalities involved.

Creative methods

Creative methods can be employed to make the research experience more fun and, in particular, to elicit the views of younger children for whom more formal or language-based activities may be less appropriate. However, careful thought needs to be given to this kind of approach to ensure the research questions can be adequately addressed, and the resulting data appropriately analysed.

Table 2: Creative methods for engaging participants in research

Drawing pictures / taking photographs (individual or group activity)	
Purpose	to visually capture an idea or concept
Ideal for	- capturing thoughts and opinions through art, which may not easily be expressed in words - CYP who prefer non-verbal methods of communication, including very young children and some disabled CYP - providing additional richness to supplement interview or focus group data
Less good for	- some older CYP, who may consider a request to draw a picture to be patronising - CYP who are uncomfortable using such methods or who feel they are not 'good' at art
Considerations	- a record will be needed of what the drawing or photograph represents to a child for analysis purposes (this could be in the form of an agreed caption, or the recording of a discussion with the child or group about what the picture means) - the cost of materials and processing (cameras, developing, printing, art materials) must be covered - if the pictures are to be used in the report or dissemination, consent must be sought at the outset (from CYP, plus parents in the case of photographs of CYP under the age of 16) - ownership of the pictures or photographs must be clarified, e.g. whether the CYP will keep a copy
Designing a poster (group activity)	
Purpose	to visually represent an idea or message through words and drawings
Ideal for	- group work - getting the CYP to focus on key issues
Less good for	some older CYP may consider a request to design a poster to be patronising
Considerations	- the meaning of the poster will need to be explained by the participants and recorded by researchers for use in analysis - consent to use the material in reporting or dissemination must be sought at the outset - ownership of the poster must be clarified, i.e. whether the CYP will keep a copy
Diary-keeping	
Purpose	to record the thoughts of CYP in words or pictures over a period of time
Ideal for	- gathering data about sensitive issues - when data needs to be gathered on a daily basis - keeping momentum and interest during longitudinal projects

(Continued over)

Less good for	• very young children • CYP who have language or literacy problems
Considerations	• cost implications of supplying the diaries • how to ensure CYP comply • whether data needs to be structured in any way, and if not, how to analyse free-form diary submissions
Guided tour	
Purpose	• to enable CYP to describe and discuss their environment by physically exploring the setting or neighbourhood in the company of a researcher
Ideal for	• very young children (e.g. those aged 2–4 years) • can also be used with older CYP
Not good for	• CYP with physical disabilities who may find it challenging to walk
Considerations	• the practicalities of recording discussion or taking notes during the tour • whether to incorporate photography and video into the tour, and how to analyse the output • informing others in the setting and getting their consent (if necessary)
Map-making	
Purpose	• to gain an insight into CYP's geographical and spatial awareness of their locality and to identify and discuss significant places
Ideal for	• for older CYP • discussing the environment when a tour is not practical
Not good for	• younger CYP
Considerations	• how the map (and any explanation accompanying it) will be analysed

Case Study 6:

Examples of creative techniques

Visual aids (pictures, photographs, storyboard, etc.) or physical props can be useful when explaining fairly abstract ideas such as the aims of the research, how the project is funded or to facilitate discussion on issues more generally.

In research to evaluate the Youth4U project, which recruited and trained young people to provide feedback and input into the provision and design of services, the image of a ladder was used to denote stages of the CYP's journey of engagement as a Young Inspector. The first rung symbolised the decision-making process, which had them join the programme originally, and the top rung their aspirations on completion.

Physical props such as a talking stick can be passed around group members to ensure that everyone has an opportunity to contribute to the discussion and to prevent more domineering members from monopolising the conversation.

A 'magic wand' was used in a study NCB conducted for the National Participation Forum to look at decision-making by children. The wand encouraged CYP to make a wish for something that they believed would make adults listen to children. CYP of all ages were happy to engage in this exercise.

Analysis and interpretation of qualitative data from CYP

When reviewing data from CYP, particularly when it is to be combined with perspectives from other stakeholders (parents, teachers etc.), it is crucial to do the following.

- Retain the child's voice and perspective. This includes ensuring that the meaning ascribed to a child or young person's comment is what was intended, as opposed to an adult interpretation of it.
- Consider validating your emerging findings with CYP if time and resources permit (for example, by having a group session with participants).
- Provide an accompanying narrative explanation from the CYP involved, whether an individual or a group, where non-textual data such as drawings or photographs are being analysed. This could involve recording discussions about what this material means to them; encouraging them to provide a caption; or taking a verbatim record of the CYP's description of their drawing.

Reporting qualitative data from CYP

Given the need for consent when conducting research amongst most CYP, their parents and gatekeepers will know which children and young people have taken part in a piece of research. This presents a risk in that individual participants could be identifiable if described or quoted in the report. NCB's approach is to deal with this through a very careful approach to reporting, changing non-material case details and selecting examples and quotes with particular care. If anonymity cannot be assured we make this clear to

participants, and where possible check whether they are comfortable with inclusion of material that might identify them.

When quoting CYP in research reports, there is often a dilemma around whether language, grammar and spelling should be corrected by the research team. The benefit of doing this makes the report immediately comprehensible to the reader. However, NCB tends to leave these elements as is, in order to better retain the young person's authentic voice. The drawback, of course, is that this approach often requires additional explanation or interpretation to be provided by the researcher, thus interrupting the narrative flow of the report.

3.3.3 Research involving observation of CYP

Observations of CYP – often in developmental settings such as early years settings, schools and home environments – can be a very useful way of gathering evidence on their natural behaviours. Observation can yield either qualitative or quantitative data.

Non-participant observation

This involves selecting a range of dimensions of interest to the research (for example, behaviours, social actions, interactions, relationships and events) to observe and record. The degree of structure to the observation will depend on your research questions and practical considerations (for example, the age of the CYP you are observing or co-researching with, the type of setting and so on). More structured observation methods tend to be used when researchers already have a good idea of the range of behaviours they will observe (depending on the research topic, there may already be a range of observational schedules and coding schemes which can be used or modified). Less structured observations can be useful in exploratory research.

Participant observation

The researcher observes the range of dimensions they are interested in (for example, behaviours) whilst immersed in the contexts in which these are occurring. Participant observation includes 'mystery shopping', a technique which can be useful when assessing service quality: for example, young researchers [see Section 4 of these guidelines] could be trained to use a service, while at the same time recording observations on various aspects of their own experience or that of other users.

Observation studies of children

In order for data to be gathered and recorded systematically (whether structured or unstructured), all members of the research team need to have a clear understanding of the key dimensions they need to observe and how to record their observations. Clear guidance and instructions are essential, especially for structured observation.

When carrying out an observation study of CYP it is particularly important to agree procedures for the following situations:

- how to observe without disrupting ongoing activities and routines

- how to refrain from participating when conducting a non-participant observation (including strategies on how to politely decline CYP's requests to talk or play with them during an observation)
- when it would be appropriate to suspend the observation and intervene (for example to prevent serious physical danger to a child).

3.4 Ethics

The NCB Research Centre adheres to the Social Research Association (SRA) *Ethical Guidelines* which are available to download <http://www.the-sra.org.uk/guidelines.htm>

We recommend that at the start of all new research projects, the project team should work through the ethics checklist and identify any potential considerations or challenges that may affect the project design. Staff working directly with CYP may need to have a Criminal Records Bureau check but requirements are changing at the time of writing.

3.4.1 Consent

Consent to participate in research needs to be gained before any collection of personal data can begin. When undertaking research in which CYP are participants, it may require several layers of permissions from gatekeepers before you are in a position to seek the consent of individual CYP and – if necessary – their parents or carers. (See Section 3.1 for further information about access and gatekeepers.)

Table 3: Consent arrangements

Consent arrangements	
Opt-in	Potential participants give their <i>active</i> consent to be contacted or to participate in a study – in other words they indicate their consent through some form of action (such as signing a consent form, or giving verbal consent to a researcher)
Opt-out	Potential participants are given the opportunity to refuse, but where consent is otherwise <i>assumed</i> . For example, potential participants may be asked to tick a box on a form or telephone us if they do <i>not</i> want to take part or to be contacted further

Whether to implement an opt-in/opt-out or opt-out consent process will depend on various factors. These include the age and/or vulnerability of participating CYP; the nature of the research burden on participants; the methodology employed; and the sensitivity of the subject. It is possible that you may decide to have an opt-out for parents but an opt-in for CYP.

Informed consent: What participants need to know

Consent to participate in research can only be meaningful if provided on an informed basis. It is the researcher's responsibility not only to provide relevant information about the research itself, and what participation will entail, but also to ensure that this is *understood* by the child.

The following checklist covers the issues about which a research participant should be informed:

- what the research is trying to find out
- the purpose of the research
- who is funding the research
- who is carrying it out
- exactly what will be asked of participants – for example, completion of questionnaires, one-to-one interviews, discussion groups
- how the information they provide will be recorded – for example, written record, audio recording, filming etc.
- what will then happen to the data (including data protection issues)
- what degree of confidentiality and anonymity is afforded (see Section 3.4.2)
- how the information will be analysed (for example, whether results are to be aggregated, individual quotations used)
- how the findings will be reported (for example, written report or presentation)
- who will see the results of the study
- the potential benefits of the study for participants or the wider community.

Potential participants also need to understand their rights to:

- refuse to participate without adverse consequences
- not answer specific questions without having to give a reason
- withdraw from the research at any point without adverse consequences.

Participants should also be provided with:

- a contact telephone number for the researcher in case they have questions about the research
- details of your organisation's complaints procedure.

Written information about the research should always be provided in advance in the form of an accessible information sheet, that CYP (and their parents, if applicable) can keep and refer to. In addition, wherever possible, the information should also be explained verbally to the child and a check made that they understand it before data collection begins.

Please note that it will not *always* be appropriate to inform CYP about *all* items in the checklist when seeking their consent, as their age or cognitive ability may preclude this. For example, very young children cannot be expected to understand about research funding or the intricacies of data protection; attempting to explain such things could be very time-consuming for the researcher and potentially alienating and overwhelming for the child. You may wish to take advice from experts as to what information it is appropriate to impart (and how best to do this) for younger children or those with learning disabilities.

In such situations, it is particularly important that parents are fully informed about all aspects of the research.

Parental consent

For most research studies involving **CYP under the age of 16**, the consent of a parent is required as well as that of the child. If possible, this should be obtained *in advance* of the child's consent (to avoid a situation in which a child has agreed to participate and subsequently finds they are not allowed to do so). Please note that while parental consent is required, a parent cannot consent *on behalf of* the child.

For looked after CYP who are on a full care order, social worker consent replaces that of parental consent (the social worker representing the local authority as 'corporate parent'). For CYP subject to other types of order, you may *also* require the consent of a parent. The social worker should be able to advise.

For most studies, the consent of one parent is adequate; however, there may be cases in which the consent of both parents (if applicable) would be necessary, for example if the research was on a sensitive topic or exceptionally burdensome, or was focusing on intra-familial relationships.

Parental consent to participate in web-based surveys

If you require parental consent to be on an **opt-in** basis (this will depend on the subject matter of the survey), the survey needs to start by asking the respondent's age. If an age below 16 is entered³, the software should be programmed to automatically ask for their parent's contact details. It is then the responsibility of the researcher to contact the parents and obtain consent, before the child can access the rest of the questionnaire.

An **opt-out** procedure for parental consent on the web is more difficult. One option would be for an age-screening question to be placed at the beginning of the survey. For CYP giving an age below 16, a message will appear asking them to consult with their parents about participating in the survey. They can then tick a box indicating that they have done so, although of course the researcher has no way of verifying whether this has happened.

³ There is no way of course of ensuring that children are entering their age truthfully; a young child could potentially bypass parental consent by claiming to be 17. For this reason (in addition to methodological reasons discussed elsewhere) web-based surveys are generally not recommended and should certainly not be used if the research is potentially controversial, or the subject matter at all sensitive.

Table 4: Parental consent - Possible exceptions and special circumstances**Situations in which parental consent may be required for CYP aged 16+**

- You should always seek a parent's or carer's consent if conducting an interview with a young person under the age of 18 in the family home
- For particularly vulnerable 16–18 year olds (for example if they have a learning disability), or if the research is on an exceptionally sensitive or troubling topic, you may also consider it appropriate to seek parental consent
- For looked after CYP up to the age of 18, consent must be obtained from their social worker

Situations in which parental consent may be waived for CYP under 16

- If the research in question (often evaluation) is integral to a project, service or intervention that the child is already involved in, and parents or carers have already given consent for the child to participate in the project, then it may not be deemed necessary to additionally obtain consent for the child to participate in the research/evaluation. Seek clarification about the nature of consent already obtained from project staff, and consider the sensitivity of the research and the burden of participation before deciding whether it is appropriate to seek parental consent. In such circumstances, you may consider *informing* parents of their child's involvement in research either directly or through the organisation (a weak form of opt-out consent)
- If seeking parental consent would potentially breach a child's right to confidentiality, for example if they were using a service such as a drug treatment agency or sexual health service without their parent's knowledge, then it may be waived

Obtaining informed consent from CYP

Obtaining informed consent to participate in research is not necessarily a single transaction between researcher and participant. For example, in a longitudinal study you may require consent from a child to all of the following (some on repeated occasions):

- consent to participate in the study in principle (and to continue, in principle)
- consent at the start of each data collection episode (for example, before an interview)
- ongoing consent throughout specific data collection episodes (for example, to continue with an interview or take part in a particular activity associated with the research)
- consent to use the data collected.

For a one-off survey, however, consent to all of the above could be obtained at the same time.

Advance consent to take part in a study (in principle)

Ideally there should be an interval between gaining 'in principle' consent and the collection of data, although this is not always possible in practice⁴. This enables the child or young person to absorb information, reflect on their decision, discuss it with others (for example, parents or carers) and have any concerns or questions addressed. The length of this interval will inevitably vary, but the age of the child also needs to be taken into account. For instance, while most teenagers might reasonably be expected to provide reliable initial consent a week or more in advance, a few days might be more appropriate for 10 year olds, and less for younger children.

Whether you use an opt-in or opt-out arrangement for consent at this stage will depend on issues such as the child's age and vulnerability, and how onerous or sensitive the research is. The research methodology is also relevant. For example, an advance opt-in should always be used in relation to qualitative face-to-face methods, as a child may find it more difficult to refuse once face to face with a researcher (not to mention the researcher's wasted time in turning up for the interview). However, it is usually not necessary to seek an opt-in for a survey; a postal or electronic survey is less intrusive and can more easily be ignored, or sent back blank, by those who failed to 'opt-out' but do not wish to participate in the research.

Role of gatekeepers in the consent process

Ideally, informed consent should be obtained directly from the child by the researcher, who will thereby be able to satisfy themselves – as far as possible – that voluntary informed consent has been given.

However, in some circumstances initial information about the research together with an invitation to the child to participate may need to be imparted by a gatekeeper (this could be a parent or a professional). In such circumstances, be alert to the possibility that pressure may be put on the child to either consent or decline. The researcher should brief the gatekeeper about the importance of voluntary consent, and be extra vigilant when confirming the child's consent on any subsequent occasion (for example, at the start of an interview).

If it is not possible for CYP to give informed consent themselves (for example, babies, or CYP with severe learning disabilities) then you should obtain consent from their parent in the first instance, if possible also agreeing signs or signals that will indicate that the child wishes to withdraw from the research.

⁴ For example, if data is being collected from users of a 'drop-in' facility or those attending a one-off event.

Table 5: Observation studies and consent issues**Observation studies and consent issues**

Consent for observation often depends on the type of observation conducted and whether or not the main focus is the setting or the CYP themselves. More explicitly, if you were planning to observe early years settings and your main aim was to get a global view of the quality of the setting – including for example, the space and furnishings, the caregivers' facilitation of children's development, and health and safety – a letter to parents informing them of the observation is often sufficient as no individual child is the focus of the observation and their specific behaviours are not being recorded. If, however, the main focus is the interaction between the caregiver and a specific child (often referred to as the 'focal child'), then direct parental and child (age-dependent) consent is necessary.

As with all research with CYP, observation may raise possible ethical concerns, mainly focusing on whether observations are conducted overtly or covertly. In the case of the latter, observers opt to conceal their presence usually because it is determined that the presence of the observer may distort the very behaviours that the observer is hoping to capture.

Researchers conducting observations need to be particularly alert for any indication that the child is uncomfortable with the research process, including behaviours that appear to make observation difficult; this should be taken as a tacit refusal of permission to be observed.

Depending on the age of the CYP, it is important that participants (and/or their parents) are fully debriefed on the nature of the observation following its conclusion – as an ethical researcher should when any type of 'deception' is used.

Obtaining informed consent at the point of data collection

Consent to collect data at any given time should not be assumed just because prior consent to participate in the study has been given. It is particularly important to satisfy yourself that the child understands that their participation is voluntary and that they have a right to refuse or withdraw from the research at any point without adverse consequences.

Please note that while verbal information about the research may be given collectively to a group of CYP (for example before administering a questionnaire to a class or at the start of a focus group), each child nevertheless needs to give their consent to participate *on an individual basis*.

Confirming ongoing consent and facilitating refusal or withdrawal

It is important to emphasise to CYP that they are free to stop participating at any stage. This includes declining to answer individual questions, not taking part in a particular activity, or withdrawing completely from the project. Therefore confirming consent is an ongoing process and should be monitored throughout data collection. CYP need to be reminded regularly that they do not have to continue participating, particularly if they show signs of distress or loss

of either interest or engagement. This is obviously easier to monitor in a face-to-face situation (but it is also possible to build in reminders that participation is voluntary within a questionnaire). Ideally, we should offer CYP the opportunity to take a break from the research and to re-engage at some point in the future – if time permits.

When collecting data face to face, the signals to be used for facilitating withdrawal should be agreed with CYP at the start of the interview or activity. For example, coloured 'stop/go' cards could be used to indicate that the child wants to ask a question, does not understand a question or does not want to answer. When administering questionnaires to a group (for example, in a classroom) it is important that there are alternative activities, or another room available, for CYP who do not want to take part or wish to withdraw. For example, you may consider providing quizzes or games on the back of questionnaires so that the decision not to participate remains private.

Recording consent

Ideally you should obtain a written record of a child's consent to take part, together with parental consent if applicable. External ethics committees will almost certainly expect this. However, if possible try to reduce the formality of the paperwork.

It will sometimes be more appropriate to digitally record spoken consent than to use paper forms.

3.4.2 Confidentiality, child protection and safeguarding

As far as possible, CYP participating in research should be afforded the same degree of protection regarding confidentiality, anonymity and data protection as adult participants. However, when it comes to matters of child protection, there is clearly a duty to ensure the safety of CYP over our responsibility as researchers to guarantee confidentiality.

Any organisation wishing to involve CYP in research should have policies in place to address safeguarding issues; specifically setting out the circumstances under which information given by a child would be disclosed in the interests of their safety (or that of another child).

Confidentiality

The limits to confidentiality must be explained clearly to potential research participants through information provided about the research and reinforced during the consent process (see 3.4.1 above).

In discussing issues of confidentiality and anonymity, CYP should also be made aware of issues concerning data protection – including the storage of any written, audio-taped, video-taped and computerised information.

For the researcher's own protection, as well as that of the child, it is important never to be alone with a child in a house or building; nor should interviews with CYP be conducted in their bedrooms. However, it is also important that the child has confidence in the confidentiality of the research process.

In most circumstances, a parent or gatekeeper would ideally be in the vicinity but not too close to where data collection occurs – within view or calling distance, but not able to overhear what is being said. However, if a child wants their parent or a gatekeeper to be present you should agree to this, and for very young children or disabled CYP, a parent or carer may need to be present to provide physical help or assist with communication. If interviewing at a service, school or a similar setting, ensure a gatekeeper is aware of your presence and use a private room, ideally one with a glass door or window.

In studies on very sensitive issues, such as alcohol or drug use or sexual behaviour, you should consider using research methods that enable CYP to contribute without risking being overheard (or overlooked, if questionnaires are being completed in an open setting). This could be done, for example, by using flash cards during an interview, providing a self-completion diary, or completing a questionnaire on a computer rather than paper.

Avoiding harm

As part of their responsibility to ensure the safety and welfare of any child or young person participating in research, the researcher has a duty to avoid or minimise any harm due to the research process itself. This involves being mindful of the possible effects on the child throughout the research process. For example, if researching a potentially sensitive or painful subject, it is important that the research method is appropriate. For example, a focus group is not usually appropriate in such situations (as the child may feel exposed), but neither is a self-completion questionnaire (as difficult issues may be raised and the child left in a distressed state without support).

The researcher should also make sure that they are in a position to assist CYP who have participated in research to access appropriate help or support, if required. (However, it is important that researchers maintain their professional boundaries and recognise the limits of their own expertise, signposting to external sources of support rather than attempting to provide support or counselling themselves.) Before undertaking interviews with CYP, therefore, the researcher should gather together information about local sources of help (related to the subject of the research, but also more generic counselling services in case the research throws up unforeseen issues for individual participants). Gatekeepers can often advise about relevant local services. This information should be made available to participants (if required), as part of a debriefing process, which should take place at the end of every interview with a child. If the research has involved discussion of painful or difficult experiences, the researcher should ensure that the child takes details of support services away with them.

4. Involving CYP in research

This section focuses on situations where CYP may be involved in the planning and process of research projects in roles *other than* as research participants.

In making decisions about CYP's involvement, issues of research quality and good participation practice need to be given equal weight. While we believe that CYP have a right to be involved in research about issues that affect them, we also need to be clear that their involvement will improve the quality and utility of the research, whilst at the same time ensuring that the experience is positive, meaningful and ethical for the CYP concerned.

4.1 Planning to involve CYP

While NCB encourages the involvement of CYP in the planning and process of research whenever possible, the nature of the research itself and budgetary or time constraints may sometimes render this inappropriate or impractical⁵. This section of the guidelines should help you to decide whether or not to involve CYP in any given research project (and if so, how best to involve them).

Once a decision to involve CYP has been made, careful advance planning is essential to ensure ethical and effective practice. This should start when the idea for a piece of research is first being discussed. Plans should also be put in place for evaluating the impact of CYP's involvement in the research.

4.1.1 Initial considerations

The first decision to be made is whether it is appropriate – in principle – to involve CYP at all in the proposed research (before any consideration of practicalities or resources). In fact it is difficult – in principle – to make a case for *not* involving CYP in *any* research which purports to be about CYP (although there may be sound arguments for only involving some, in certain ways, at specific stages. NCB's starting point is always to assume that CYP will be involved in some way, unless a strong case can be made to the contrary.

What model(s) of involvement would be appropriate?

Whether CYP are to be consulted, collaborate or have ownership of the research will depend on a number of factors, including:

- the views and preferences of the CYP themselves (if involved at this early planning stage)
- how the research is funded
- the proposed methodology (if determined at this stage)
- practical constraints (such as resources and timing).

⁵ In such cases it is always worth stating briefly in a proposal our commitment to involving children in research, together with our reasons for not proposing to do it on this occasion.

At what stage(s) of the research, and in what roles, would CYP's involvement be appropriate?

This will be influenced by:

- the views and preferences of the CYP themselves
- the methodology (the technical complexity)
- ethical issues (for example, in relation to the subject matter of the research and the age of the CYP involved)
- practical constraints (such as resources and timing).

Who is it appropriate to involve?

In the 'ownership model', CYP themselves make decisions (guided, if necessary, by adults) about how and when they – as a group, and as individuals – will be involved in the research. It is the adult researchers' responsibility to ensure the appropriateness of the proposed involvement (that is, whether it is ethical, and likely to be of benefit to the research process).

In other situations, decisions will need to be made about which CYP it would be most appropriate to involve, based on:

- their age and maturity (bearing in mind the focus and subject matter of the research)
- the specific skills or abilities required (although the onus is on the adult researcher to make the process accessible and provide relevant training, in certain circumstances particular skills such as a degree of literacy might be considered a prerequisite)
- the relevant personal characteristics or experiences they bring to the research (for example, being disabled or looked after)
- their individual interest in getting involved
- the implications for the size and composition of the group (for example, avoiding a group with a very wide age range to ensure that activities are both accessible and stimulating for all members)
- practical constraints (such as resources and timing).

4.1.2 Resourcing

Before plans are taken any further, it is necessary to ensure that adequate resources are in place or can be secured. This may entail arranging to cover some or all of the following:

- transport and other expenses to enable CYP to attend meetings, training, carry out fieldwork and so on
- (if appropriate) expenses for personal assistants to support disabled CYP's involvement
- costs for interpreters or translators, if involving CYP who do not speak English as a first language
- the cost of producing resources (printing, photocopying and so on)
- courier costs if materials need to be delivered offsite
- room hire, equipment and catering costs (for meetings)

- accommodation costs if hosting a residential course
- rewards for CYP (in the form of vouchers)
- accreditation costs (if appropriate)
- staff time (almost certainly more than you might at first expect) to recruit, train and support CYP in their roles:
 - o communicating with CYP throughout the project (including follow-up and chasing)
 - o communicating with parents (for CYP under 16)
 - o planning training or other activities
 - o providing ongoing support (for example, while CYP are involved in data collection)
 - o producing resources
 - o attending meetings or events
 - o booking venues and arranging transport.

Resource limitations may require you to modify your plans (for example, to involve locally based CYP instead of a more representative national group in order to limit travel and subsistence expenses).

4.1.3 Practicalities

Once you have decided which CYP to involve you will need to think through the practicalities and plan accordingly.

Recruitment

For CYP to make an appropriately informed decision about whether to get involved in a research project, it is important to provide comprehensive and accessible information about the study and the proposed role(s) of CYP within it.

Key information is typically provided as a leaflet and would include:

- a description of the types of CYP you want to recruit (for example, age, location, particular skills or characteristics etc.)
- specific activities they would be engaged in and level of involvement
- purpose of the project and the role of CYP
- nature of the commitment (when, where, how often, how long for etc.)
- how to apply or where to find out more.

In addition, a simple application form can be developed to collate basic information on those volunteering to take part in order to facilitate sampling and recruitment decisions. For CYP under 16 consent will also be required from parent/carers at this application stage.

The interests and availability of CYP can also change over time, so if the project is running over more than 6–12 months you may need to plan for further recruitment to replace CYP who decide to leave the project.

Producing recruitment materials and other information

Materials designed for CYP need to be age-appropriate, accessible to the particular target group and take account of language and cognition skills. Depending on the group or groups you are working with, it may be necessary to produce them in different versions, formats or languages.

As a general guide, it is important to do the following:

- include only essential information
- use plain English, keeping sentences short, clear and to the point
- use everyday vocabulary and avoid jargon (or provide an explanation where this is unavoidable)
- use headings to break up the text and organise the information into clear sections
- make the materials eye-catching, for example make use of colour, illustration and symbols (for example, faces to denote feelings)
- it is usually best to avoid 'youth speak' or text shorthand as this can be perceived as patronising.

It may be useful to check in advance, with CYP themselves or a gatekeeper, whether the design and language of the materials are appropriate for the CYP with whom you will be working. This is particularly important when designing materials for CYP who have special educational needs or a disability.

Making reasonable demands

It is important to anticipate the likely availability of CYP when planning their involvement (and ascertain their availability individually, once they are involved). This means that researchers may occasionally need to work in the evenings or at weekends to overcome the inevitable issue of CYP's lack of availability during normal working hours in term-time.

Furthermore, it is important to ensure any demands or commitments placed on CYP are reasonable and proportionate. Social and family life, study, hobbies and relaxation must all be allowed to take priority.

Communication between meetings or activities

The frequency with which a group of young researchers or advisors will need to be convened will inevitably vary according to the requirements of a particular project and the commitment of the group to the objectives. In NCB's experience it is viable for a project group to meet every 6–8 weeks, but in some cases 3–4 times a year would be seen as onerous. Best practice is to negotiate this and secure appropriate commitments from those intending to participate at the outset of a project.

Irrespective of the frequency between meetings, it will be important to consult or keep in touch with group members individually or as a group. Again, both the means and frequency of communication would ideally be agreed at the outset and kept under review.

CYP can be kept informed and engaged via a combination of emails, letters, text messages and internet communication. However, it would be unwise to expect CYP to behave like adult professionals in acknowledging or replying to

communications promptly! A 'belt and braces' approach is often necessary, for example sending a text message to remind CYP to check their email.

4.1.4 Policies and procedures

Because of our extensive involvement with CYP in research and participative activities, the NCB has a wide range of policies in place to safeguard children and their rights in this respect. Although it is not appropriate to reiterate these policies in detail here, you may wish to use this summary as a rough guide to what you may need to have in place.

Personal information and data protection

You will need contact details for all CYP involved in your research project. In addition you will need to have a record of:

- their date of birth
- the emergency contact details for their parent or carer
- any special needs or dietary requirements
- relevant medical information (for example, on allergies and medication)
- their NHS number and GP's name and address.

This information can be collected in a single form (ideally at the same time as obtaining formal consent, see below) and should be secured in accordance with Data Protection guidelines, that is, electronically in a secure folder or, if in hard copy, in a locked filing cabinet.

CYP's consent

You need to keep a record of every child's consent to take part in your project. Consent needs to be gained on an opt-in basis and a written record kept.

You can obtain rolling consent if CYP are going to be involved in a project on an ongoing basis, as this avoids the need to obtain consent for every meeting or activity that the child is involved in. However, even if you have secured rolling consent at the start of a project, it is important to regularly review it. Information about the project should be provided alongside the consent form (so that CYP are clear about what they are consenting to).

If it is possible that photographs or digital images of CYP will be included in reports or other materials arising from the project, consent for this can be requested as a separate item within the consent form.

You will need separate consent forms for CYP in residential accommodation.

Agreement or informal 'contract' with CYP (optional)

Alongside a consent form it can also be helpful to have a written agreement or informal 'contract' with the child, one that clearly states what is expected of them and what they can expect from the adult research team in return.

Travel arrangements

In addition to consent to take part in an event⁶, parent/carer consent is also required in relation to the child's mode of travel (from door to door).

CYP may travel to the event by a variety of means, including rail and air transport. Wherever possible CYP should be accompanied by an appropriate adult (such as a staff member, parent/carer, or other participant). There must always be an appropriate adult travelling with CYP under the age of 16 unless alternative arrangements have been agreed with their parent/carer and in such a situation parents/carers will need to sign a letter detailing the arrangements and taking responsibility for them. Parents will need to be informed about the insurance implications of their child's travel arrangements.

Particular care must be taken in making arrangements for safe travel to and from an event when young people are travelling unaccompanied by public transport. The arrangements will depend on the age and maturity of the young person, length/complexity of the journey, experience of travel, and so on, and should be discussed, risk assessed and agreed with all relevant parties as part of planning for the event. Where a young person is not accompanied, contingency plans should be made to ensure the young person is clear on what to do and who to contact should there be any problems en route to the event. This could include sending each child an emergency contact card detailing relevant details for the organisation HQ as well as mobile numbers for individual researchers and details relating to the venue. A text to follow up on young people at the end of a training session or residential course, to ensure they got home safely, is also advisable.

Medical treatment

On the rare occasion that a child involved in a research activity requires medical treatment, only the child, their parent(s)/carer(s) or a doctor can make a decision on treatment. If a parent is not available, the doctor will judge if the child is competent to consent to treatment. If a child is under 16 their ability to consent to surgical, medical or dental treatment is decided on a case-by-case basis, according to whether they are judged to be 'Gillick Competent'.

Risk assessment

When CYP are expected to attend an external event, it is usual to conduct a risk assessment prior to the event. The purpose of the risk assessment is to:

- identify things that might go wrong
- make contingency plans
- identify risks that can be avoided.

Most external venues will have their own risk assessment but, in such circumstances, it is good practice to carry out an organisation-specific assessment so that you are able to share this with parents and carers during the consent phase or in the event of an emergency.

⁶ Including meetings, conferences, residential courses, etc. associated with the project.

Record keeping

In addition to drawing up a risk assessment, it is good practice to compile a register of CYP who are expected to attend the event or training session. The register should include:

- the name of the child
- the time they are due to arrive
- their mode of transport
- their contact details (including mobile numbers)
- details of their parent or carer
- a note of any dietary or disability requirements
- medical information, including medication and allergies.

4.1.5 Induction, training and support

Whatever role CYP will be taking, it is imperative that they receive adequate training to prepare them for their role, and ongoing support throughout the process. A group of CYP will also need time to get to know each other, and the adult researchers, before effective work can begin. Time for this, including 'ice-breaking' activities and 'energisers', will need to be factored in when planning.

CYP need to be prepared for their role by having:

- a general briefing about the project
- an introduction to the other people involved (adults and CYP)
- an understanding of their role and what it entails
- the development of skills to undertake this role.

It should **not** be assumed that CYP will necessarily have fully absorbed or understood the written information provided at the recruitment stage. Everything will need to be explained again fully.

Planning training: General issues

- Don't underestimate the amount of **time** needed to plan an effective training session (one trainer of trainers suggests a ratio of 6 hours preparation for every 1 hour delivered).
- Start by focusing on the **objectives** (or learning outcomes) for the session: exactly what do you need to achieve by the end of the day?
- The training needs to be both **accessible** and **enjoyable** (a dry 'lecture' format should be avoided – keep PowerPoint to a minimum); and tailored to the age and cognitive ability of the CYP involved.
- Remember that different individuals have different **learning styles** (for example, some learn through listening, others through visual aids, and some by actively 'doing'). Try and incorporate a range of approaches during the session.
- While some **variety** is important, don't go overboard and cram too many participatory methods into a session with CYP as this can be overwhelming.

Planning training: For young researcher roles

- If they are to be involved in data collection, ensure that young researchers are given the chance to role-play being an interviewer or focus group co-coordinator.
- You will need to ensure that they understand the ethical issues involved in data collection, including data protection, safeguarding and any ethical issues relevant to the research topic or methods.
- CYP also need to be aware of power issues in relation to peer-led research, and their implications in relation to ethics (for example, respondents feeling obliged to participate) and bias (for example, an expectation to respond in a particular way).

Case Study 7:**Youth4U Young Evaluators**

To make CYP aware of some of the challenges and pitfalls of conducting a focus group interview, and to provide them with practical strategies to use, the 14 young evaluators on the Youth4U project were split into three groups and in each group, one young person was appointed to be the interviewer. The other respondents were asked to draw, from a lucky-dip bag, a piece of paper on which was written a role for them to act out in the group. For example, one role entailed looking uninterested and playing with their mobile phone. Another role required enthusiasm to the point where they would not allow others to speak.

The aim of the exercise was to show how difficult it can be for an interviewer to manage the different types of individual who may be encountered during a group interview. This exercise was repeated and the roles were swapped, so that everyone in the group had the opportunity to lead the discussion and participate in the role-play. The trainees were then encouraged to produce a list of top tips for conducting group interviews.

4.1.6 Reward and recognition

Whenever CYP are involved in research activity they should receive appropriate rewards and recognition. For ad hoc participation in focus groups, for example, high-street gift vouchers would be an appropriate 'thank you'. Where their participation has required more time, such as membership of an advisory group, it may be appropriate to offer a larger financial incentive.

Other forms of reward include a certificate acknowledging their contribution at the end of a project. As many CYP use such certificates in their portfolio or as evidence for university or other applications, it is helpful if these are personalised and provide detail of the specific training and activities an individual young person was involved in.

For extended involvement in longer-term projects, you may want to consider exploring formal accreditation, for example through ASDAN or the Open

College Network. This can be a very effective and appropriate way of acknowledging the work of individual young people, particularly those from disadvantaged groups. There are inevitably time and cost implications, however, which need to be explored before these opportunities are publicised.

4.2 Ethics

The same broad ethical principles apply to involving CYP in the research process as when they are participants in research: CYP should be fully informed about what involvement entails; and their safety protected at all times.

4.2.1 Informed consent

Specific procedures around consent (including parental consent) have already been set out in Section 4.1.4.

As involvement in research is more likely to entail a commitment over time, however, consent may need to be reaffirmed regularly (though not necessarily formally) throughout the project. Should a project develop in unanticipated ways, perhaps offering a range of new or different opportunities for CYP to become involved in it, it would also be important to establish (rather than assume) consent to these changes.

If CYP decide they no longer wish to be involved, it is important to respect that whilst offering them the option of taking a break and re-engaging at some point in the future.

4.2.2 Child protection and safeguarding

Specific safeguarding issues when CYP are carrying out research

If CYP are to be involved in data collection as part of their work on the project, serious consideration needs to be given in advance to ethical issues that may arise and how they will be dealt with. Specific procedures will need to be agreed and accessible written guidance produced.

In particular, CYP need to be thoroughly trained, briefed and supported in relevant aspects of research ethics, including:

- informed consent
- confidentiality
- child protection procedures (for example, if a research participant discloses abuse to them during an interview)
- monitoring and dealing with distress (for example, if an interviewee becomes upset).

In addition, consideration will need to be given to the safety and well-being of CYP while they are undertaking fieldwork, including:

- ensuring that they are not placed, or put themselves in, risky situations

- providing them with the contact details of members of the research team during agreed fieldwork times
- debriefing them after each fieldwork session.

4.3 Involving CYP in stages of the research process

This section addresses the specific issues associated with involving CYP in different stages of the research process, with reference to the different models of involvement outlined in Section 2.

4.3.1 Proposal writing and research design

It will not always be possible to involve CYP at the proposal-writing stage for practical reasons. Invitations to tender often have a very rapid turnaround time, precluding the possibility of convening a group within the timescale allowed.

Depending on funding arrangements and timing however, CYP could be involved in:

- helping to focus ideas or generate research questions
- advising on methodology from their perspective as potential sources of data, that is what will and won't 'work' in practical terms
- advising on dissemination plans (particularly to other CYP)
- commenting on a draft proposal in its entirety.

When CYP are involved as collaborators or have ownership of the research, they will inevitably have more influence over the research design and methodology, although in both cases this will need to be done with advice, guidance and possibly some formal training provided by adult researchers.

Case Study 8:

C4EO and YRN young researchers

In both of these projects, the young researchers received training on different research methods; and discussed the pros and cons of various alternatives in relation to the research questions. As part of the learning process, they did a role-play on participation in interviews and focus groups. In both instances, the groups decided on a web-survey.

4.3.2 Advisory groups

CYP have been effectively involved in research projects as part of an advisory or steering group: either as a dedicated CYP group or as representatives on a broader stakeholder group.

Key issues to consider when setting up such groups include the:

- overall responsibility for hosting, administration and expenses
- composition
- frequency of meetings
- terms of reference
- desired outcomes.

Either model provides opportunities for CYP to influence aspects of the research programme but different issues are associated with each model. Also, the amount of support and preparation required for such groups should not be underestimated. Table 3 sets out some of the issues and challenges, and shows that involving CYP in a wider group is not necessarily the 'easier' option.

Table 6: Models for CYP representation in advisory groups

	CYP represented on wider group	Dedicated CYP's advisory group
Conduct of meetings	Considerable adaptation required to make meetings accessible to CYP (timing, pace, agenda, language etc.). Some adults may be unwilling to adapt their behaviour	Can be planned with CYP in mind, but fewer issues likely to be covered
Supporting CYP's involvement in the group	CYP will need to be briefed in advance of, and supported during each meeting (e.g. to ensure they have opportunity to speak when they wish to contribute to discussion)	No additional support required, as meetings will be designed for (and to some extent by) CYP
Language and paperwork	Child-friendly versions (or summaries) of papers will need to be produced. Supporting adults may need to be on hand during meetings to 'translate' technical terminology to CYP	Child-friendly versions (or summaries) of papers may need to be produced, though it may be possible to limit need for papers more generally. Technical language can be avoided altogether
Role and influence	This kind of group likely to carry more 'weight', but risk of tokenism and of CYP's voices not being heard	Clear messages from CYP should emerge, but on a narrower range of issues. A parallel adult group may be more influential

Clear information and briefing in advance

In order to obtain informed consent, clear information about the group will need to be provided in advance to potential members. **Remember that CYP are unlikely to be familiar with this type of group or with formal meetings more generally.**

Such information should include:

- information about the research project
- how many meetings they will be expected to attend and how frequently
- where and when these meetings are likely to take place
- how long the meetings will last
- who else will be involved (Other CYP? Adults? How many?)
- what types of issues the meetings will cover
- what will be expected of group members (for example, reading papers in advance, attending every meeting or giving apologies)
- terms of reference for the group, or some indication of the level of influence of the group (for example, whether advisory or steering).

Maintaining interest

CYP may lose interest in a project if they are not in regular contact with the project lead. To avoid this happening, NCB recommends a combination of the following strategies.

- Be clear at the outset what is expected from their participation.
- Tailor roles to individual areas of interest. For example, they may want to be a co-chair; note-taker; or be responsible for marketing or communications and undertake related tasks that align with the role (for example, designing a logo or writing an article for publication).
- Send regular updates to keep them in touch with what is happening on the project.
- Don't make unreasonable demands on their time, e.g. allow adequate time to comment on research materials or the report.
- Review progress, give feedback on findings, and make changes to processes and responsibilities on a regular basis to ensure that the group is meeting the expectations and needs of both CYP and the research team.

4.3.3 Developing research tools

The design and development of data collection tools is often something that young researchers are keen to get involved in, as this gives them a direct stake in the research and the questions being asked. CYP will often have a very different perspective on how to approach particular topics, the feasibility or relevance of proposed questions and the appropriate language to use. They may well also come up with innovative and creative ideas for eliciting data.

CYP can be involved in:

- drafting research tools (with training and support from adult researchers as required)
- informing the structure of research tools (the order of questions, for example)
- drafting or commenting on survey, interview or focus group questions
- advising on the presentation and layout of questionnaires
- piloting research tools developed by or with adult researchers.

Case Study 9:

C4EO and YRN young researchers

Both these groups proposed web-based surveys to support their own particular research objectives. Questionnaires were developed through an initial brainstorming phase, with the CYP identifying key research questions which were then worked up into a survey format by researchers. The draft surveys were then further developed by the CYP and adult researchers, in consultation with project sponsors. The groups were also involved in piloting the surveys and agreeing the final versions.

The ways in which CYP are involved in developing tools will vary according to the requirements of the particular research project and the model of involvement employed. Regardless of the model, however, it is important that CYP are clear about the limits of their influence. Whichever model is in operation, adult researchers have a responsibility to ensure that the tools produced are methodologically appropriate and ethical, and that the overall research design remains feasible and meets contractual obligations.

4.3.4 Recruitment of research participants

There are two main ways in which CYP can be involved in recruiting research participants: indirect and direct.

Indirect involvement can relate to content and design of recruitment materials. CYP can play an important role in ensuring that recruitment materials are accessible in terms of language and layout; include relevant information; and are sufficiently persuasive to encourage other CYP to participate in the research. CYP's involvement might range from simply commenting on drafts produced by adults, to designing and producing their own recruitment materials (with adult support and guidance as appropriate).

Direct involvement can be through recruiting other young people themselves, in accordance with an agreed strategy. The extent to which CYP can be directly involved will depend largely upon the methodology in question: for example, if the methodology requires a random sample, involvement would not be appropriate. There may be opportunities for involvement in qualitative studies and, in some cases, CYP may be able to reach specific populations in ways that are less accessible to adults.

Case Study 10:

Get Ready for Change

As part of the Get Ready for Change project run by the Children's Rights Alliance for England (CRAE), a group of CYP were involved in designing and implementing a sampling strategy for some research they wanted to carry out to examine the availability of counselling services in schools. To enable them to do this, the young people were given a short PowerPoint presentation on the pros and cons of purposive sampling, convenience sampling and snowballing sampling. After discussing these strategies, the group opted for snowballing primarily because of the contacts they had through social networking sites. They decided to post a link to an online survey which they would send out to their contacts, who in turn would be asked to pass it onwards to their friends and so on. As the research was England-wide, this method of communication was deemed the quickest and most cost-effective way of getting other CYP from across the country to participate.

4.3.5 Data collection

Collecting primary data is something that CYP are generally keen to get involved with, and is what many associate with 'doing research'. However, involving CYP in this aspect of the research process is not something to be entered into lightly.

Before deciding whether or how CYP could be involved, consider the following (either at the proposal stage or in consultation with the CYP concerned, depending on the nature of the research and the model of involvement):

- the **subject matter** of the research – it may have implications for who it is appropriate to involve, or whether to involve CYP at all (for example, it probably would not be ethical or appropriate for CYP to be interviewing in studies about bereavement or child abuse, and they may not be interested in carrying out interviews focusing on the minutiae of how services are commissioned)
- **who** the data will be collected from – will CYP be gathering data from their peers (those of a similar age or experience), other CYP (with whom they may have little or nothing in common) or adults, such as parents or practitioners? There will be different practical, ethical and safeguarding implications in each case. Consideration should also be given to the power dynamics involved in the data collection process (for example, if CYP are interviewing adults or others who are older than themselves)
- the research **method** to be used
- **how** the data collection will take place – will CYP be doing this alone, in pairs or alongside adults?
- the nature of any **bias** that involving CYP might introduce (or mitigate) – also, how important this would be for the study in question. For example, using CYP to interview their peers might improve the quantity

of data, due to CYP being more likely to participate and open up, but reduce the quality, due to limited interviewing skills

- the **skills** required for the particular data collection method – and whether sufficient time and resources are available to train CYP to an appropriate level
- child protection and **safeguarding issues** – for example, if CYP are carrying out face-to-face interviews on their own
- the **timescale** during which data needs to be collected – and the availability of CYP during this period
- the **amount of data** required (number of interviews, etc.) – which needs to be set against the amount of time each child can commit to the work
- **reward** or payment options – will CYP be paid for their contribution and, if so, how (money or vouchers) and on what basis (per day, per completed interview)?
- **ethical** issues.

CYP will need to be thoroughly inducted, trained and supported for whatever role they take in data collection (see Section 4.1.5).

Case Study 11:

Young Researchers Network (YRN)

Young people were recruited by NCB to train as young researchers and undertake research among their peers. The initial training included taught sessions covering the range of research methods and the basic principles of research ethics. They also did role-play exercises to train them in focus group facilitation. Other exercises involved designing and developing a topic guide and other stimulus materials for a focus group, including use of participative techniques (e.g. drawing together news articles portraying CYP in the media and using these as the basis for discussion).

The group then went on to set up and conduct a real-life focus group, with the young researchers suggesting a venue and networks that could be contacted for recruitment. The young researchers introduced the sessions and took the lead as discussion facilitators, supported by an adult researcher. The adult's main role was to act as a source of support during the session and also to ensure that ethical and safeguarding protocols were adhered to.

4.3.6 Data analysis and interpretation

Involving CYP in basic data analysis or interpretation of findings can be a useful way of ensuring that research takes account of CYP's own insights and perspectives. The extent to which it is possible or appropriate to involve CYP in this analysis or interpretation of the data depends very much on the nature of the research and the interests of the CYP involved in the project. As always, the test is whether CYP's involvement can be both meaningful for the CYP involved *and* beneficial to the research in question.

If the project is collaborative or CYP-owned, then it is important to provide some opportunities for involvement in the analysis process, and to do so in ways that are as accessible and interesting as possible. Discuss with the CYP in question if and how they would like to be involved, and ensure that appropriate support and training is provided.

Remember that data analysis is a skilled job, requiring an understanding of underlying theory and principles as well as the application of technical skills; most professional researchers have had several years' formal training as well as the benefits of on-the-job experience. It simply isn't appropriate or realistic to expect young people to acquire even a fraction of these skills, or to undertake the same tasks expected of adult researchers (and this will also need to be communicated to the CYP).

The role of the adult researchers is therefore to use their experience and understanding to identify appropriate ways in which CYP can be meaningfully involved in the analysis process and to provide sufficient training for them – so they understand what they are doing, why they are doing it, and how their input will feed into ongoing or future analysis – and to facilitate and support the involvement itself.

Case Study 12:

C4EO Young Researchers

This group of eight young researchers had been involved in designing an online survey on the impact of discrimination on their peers' educational attainment. An initial training session introduced them to the key principles of analysis. This included an exercise where they were given a box of Quality Street and asked to think about all the different ways in which they could be categorised (for example, by colour, shape, hard or soft centre, whether the wrappers were shiny or not, the ones they liked and didn't). Thus they were encouraged to start thinking about how data could be organised in gross and more subtle ways; the concept of sub-categories; and that different individuals may approach the task in different ways, according to their own perspectives and interests.

The group was then given a printout of the frequencies from the online survey and shared their thoughts on how the data helped to answer their research questions. They also made suggestions for further analysis (for example, cross-tabulations) where they thought it would be useful to see if and how data was linked. Some CYP were subsequently involved in producing graphs of the quantitative data for presentation in the report.

For the final part of the session the group was given some guidance on thematic analysis of qualitative data, then cards were given out with the responses to some of the key open-ended questions. Referring back to the Quality Street exercise and guidance on thematic analysis, the CYP grouped the data and identified possible themes. These themes were used as the basis for a framework by which the analysis was continued (by adult researchers) with further input from some of the group members.

Some possibilities for involving CYP in qualitative and quantitative research are set out in Table 7. See also Case Study 13, for an example of CYP involvement in a literature review.

Table 7: Possibilities for CYP involvement in analyses

Quantitative analysis	Qualitative analysis
• data entry (for simple questionnaires) • basic grouping and coding of open-ended responses • commenting on basic descriptive analysis (e.g. frequencies), and developing hypotheses or suggestions for additional analysis • advising on presentation of findings (e.g. charts, diagrams, tables)	• identifying basic themes for adult researchers to use in analysis • commenting on or prioritising themes identified by adults • commenting on emerging findings, and developing hypotheses or suggestions for additional analysis • identifying or selecting quotations to illustrate specific points

Case Study 13:

PEAR: Literature review

The PEAR group worked with the EPPI Centre on two systematic reviews about childhood obesity. Following a training session, which gave them an overview about literature and systematic reviews, they were given large colour posters of the themes identified (by the EPPI researchers) from an initial trawl of the literature. The group was invited to discuss the themes, add comments using sticky notes and to add any themes or issues they thought were missing. They were then given five dot stickers each and asked to use these to vote for the themes they thought were most important.

This session was written up and used by EPPI to inform the second stage of the review, where the themes were finalised, enabling them to reflect the priorities and views of the group in the subsequent analysis of the literature.

4.3.7 Reporting research findings

There are a number of ways in which CYP can be involved in the reporting of research findings.

Active involvement in the production of reports and other outputs

The type of report and the level of involvement of CYP will, to a large extent, be determined by the type of research, the intended audiences, and other factors such as funders' requirements. Generally, the writing of a full formal report will need to be led by adult researchers, although ideally there would be ample opportunity for CYP to input their comments and contributions.

CYP could potentially be involved in:

- writing or co-writing sections of the report
- contributing a section about their experience of being involved in the project, why they got involved and what they learnt
- helping to develop the structure and format of the report
- commenting on and contributing to the layout and design (for example, designing a front cover, or helping to produce graphics)
- deciding on a title
- producing a young person's summary of the full report
- producing outputs in other formats (for example, PowerPoint presentation, video) communicating key findings to CYP.

Case Study 14:

PEAR: Reporting research findings

The PEAR group has been involved in producing a number of publications. The pilot group produced a young person's version of a report by the Association of Young People's Health in Europe. The full report was initially summarised by researchers, who then worked with the group to identify the key issues they thought were important to their peers. The group went on to develop a mock-up of how they wanted the summary to look. This was then sent to a professional designer who produced a draft, which was agreed by the group, then printed.

Following a conference workshop at which PEAR members co-presented, we were invited to write a book chapter. Following discussions with those CYP who wanted to be involved, it was agreed that they would each write a section on their experiences which would be included as a text box in the chapter. They also had the opportunity to comment on the draft chapter before submission. Where contributions needed to be edited, the amended versions were sent back to the young person concerned for their approval before the chapter went to press.

Case Study 15:

C4EO and YRN young researchers

In both these young people-led projects, young researchers were involved in writing the final reports. The extent of their involvement varied according to their other commitments but in each case the process was agreed with the CYP at the outset. The CYP were asked what they wanted to do and what they would prefer the adult researchers to take a lead on. It was agreed that the adults needed to take ultimate responsibility for quality and ethical issues. Those who wanted to were then involved in writing sections, commenting on the draft report or agreeing the final version prior to publication.

If adult researchers are to retain editorial control of the report, CYP need to be made aware of this from the outset. The extent of their control and input will depend on the nature of the project as outlined above, but it is important that CYP are involved in discussions about changes to their contributions, and that decisions (together with the reasons for them) are communicated clearly.

Commenting on draft reports produced by adult researchers

In most situations, CYP will not have a great deal of involvement in actual report writing. Even in the model of involvement in which CYP have ownership of the research process, it is more than likely that they will wish to delegate some or all of the writing to adult researchers. However, in all models, CYP who have been involved in the research should be given an opportunity to comment on the report.

A formal research report can be daunting for adult readers, and even more so for CYP. So rather than just sending them the whole report and asking for comments, it is necessary to make the process more accessible, for example by seeking feedback on specific sections (or one section at a time) and by providing a structured format for commenting.

In order to focus discussion, or written comments, a set of questions should be provided. For example:

- Have we answered the questions we set out to at the start of the project?
- Have we given people enough information about how we did the research, and how CYP were involved?
- Do you think that what we've written in the report reflects what people told us in the survey/interviews/focus groups? Is there anything important you think is missing?
- What do you think should happen next (e.g. recommendations)?

Ideally, the report should be discussed in a group session, but for practical reasons this may not be possible and feedback will need to be gathered by post or email.

Case Study 16:**CAMHS**

As part of a national review of Child and Adolescent Mental Health Services (CAMHS), NCB organised a reference group of young mental health service users. The group was given a young person's version of the draft report, which included findings from interviews and focus groups with other young service users. They were asked to comment on the report and to make recommendations, based on the consultation findings, on how CAMHS services could better meet the needs of the CYP who used them. These recommendations were then incorporated into the final report to government.

Making recommendations

Whatever the model of involvement, it should be possible for a group of CYP to be involved in making recommendations on what they see as key issues for their peers, particularly if they have been involved throughout the research

(and adequately briefed at each stage). Even if their only involvement is at this late stage of the process, providing the research findings are presented to them in an accessible way, CYP should still be able to comment on the implications.

Sometimes CYP will have a particular interest in or perspective on the research, for example if it is focused on a specific group of CYP such as the users of a service.

CYP should be made aware that recommendations need to:

- be directed at the main audiences for the research
- be based on findings presented in the report
- reflect the views of participants in the research, not their own opinions
- be achievable and realistic, though they can of course still be ambitious!

4.3.8 Dissemination

CYP are often really keen to have a role in the dissemination of research that they have been involved in. It's a way to make sure that their research gets heard about and is more exciting than writing reports! Depending on the project, the resources available, the model of involvement, and the wishes and interests of those involved, CYP could potentially be involved in a range of different kinds of activities. This could include developing a dissemination strategy or more active involvement in some of the dissemination activities themselves.

Ways in which CYP can be involved in dissemination include:

- identifying potential target audiences
- developing a web page on the project or text for a website
- writing or contributing to press releases
- distributing summaries, posters or other outputs to their peers, either at school or college or in services they use
- giving presentations or co-presenting at conferences or seminars
- helping to organise a conference or seminar based on the research
- identifying other opportunities for dissemination as they arise.

The key principle here is to make sure that dissemination possibilities are discussed and planned for from the outset, and that CYP are involved in the process from the earliest stages. Not all CYP will want to be involved in the same ways (and some may require additional support and training), so ideally a range of options and roles should be offered.

Case Study 17:**PEAR: Dissemination**

The pilot group identified dissemination as a key priority for CYP's involvement in public health research, as they felt that a lot of really important research is done about young people and public health by adult researchers and disseminated to other adults, but that CYP were excluded from this process. Two key elements of the project were the development of a website and a conference, each of which were aimed at both CYP and adult public health researchers. Group members were involved in designing and providing content for the website; helping to plan and publicise the conference; giving presentations and running workshops; and meeting and greeting delegates on the day.

Case Study 18:**YRN young researchers**

One of the young researchers involved in this project – on the portrayal of young people in the media – had web design experience and designed a web page, flyer and poster about the research findings. The Young Researcher Network, which supported this programme of young people-led research, organised a conference for all the projects in the network; and the NCB young researchers planned and prepared a workshop which two of them then delivered. Following the completion of the project, a number of other opportunities have arisen: including a request by the Open University to turn the group's report into a chapter in a book used on one of their degree courses (with the young researchers credited as authors); and several invitations to speak at conferences. We have passed these invitations on to the young people involved and, providing they were interested, supported them as necessary.

5. Review and evaluation

In this final section we discuss the issues you need to consider in monitoring and evaluating research with CYP.

5.1 End of project review

NCB recommends that some element of critical reflection should take place on the completion of all projects. This is particularly important for research with CYP, as researchers have an ethical and moral responsibility to ensure that any involvement of young people is robust, rigorous and safe.

If CYP were participants in the research, it would not be appropriate or practical to involve them in the review process. However, if CYP were *involved in* the research process itself, then ideally their reflections would be captured in an end-of-project review process, either individually or as a group.

5.2 More formal evaluation of CYP's involvement in research

There is currently only a very limited evidence base on the impact of public involvement in research (that is, involvement in the planning and process of research rather than as participants). Much of the focus thus far has been on the impact on the individuals involved (not least because this is easier to measure), rather than on the quality, utility or impact of the research itself.

Whenever possible, resources permitting, we should seek to improve the evidence base by evaluating the impact on our work of involving CYP in research.

CYP could contribute to the evaluation of their involvement in a research project in the following by:

- giving their views, as evaluation **participants**, via feedback forms, questionnaires or focus groups
- being **involved in the evaluation process**, for example, by:
 - o helping to define the aims and objectives of evaluation
 - o developing indicators and measures
 - o undertaking data collection
 - o commenting on draft evaluation reports
 - o peer reviewing, as a group of CYP, the research process and outcomes.

Case Study 19:**PEAR: Evaluation**

The PEAR project, in the same way as the pilot that preceded it, has a small evaluation project running alongside it. This is being undertaken by two members of the Centre who are not involved in project delivery. It is a formative evaluation, with PEAR's CYP having opportunities to be involved in the evaluation process from the outset – including agreeing aims, objectives and methods; and commenting on tools. They are also contributing as participants – completing evaluation forms at the end of each meeting (which were revised following their feedback on the data they thought the evaluators should be collecting) and taking part in evaluation focus groups at two key stages in the process. The evaluation will be written up as a chapter in the final project report, and again group members will have a chance to contribute to this.

Case Study 20:**Youth4U Young Evaluators**

Fourteen CYP, aged 14–19 years, were recruited to help evaluate the Youth4U Young Inspectors project. The young evaluators received training on research methods, how evaluation differs from research, designing data collection tools and carrying out fieldwork. The young evaluators will also be giving their input into the design of adult surveys and future data-collection instruments that will be used during follow-up area visits. To maximise CYP's input into this evaluation, we will be inviting the young evaluators to choose a role when writing up their evaluation. They can apply to be a designer (helping design the layout of the report); writer (writing the report chapters); illustrator (assisting with graphs); work in communications and publicity; or take responsibility for dissemination of their report. They will also be involved in evaluating their own role in the project, which will be fed into an additional assessment of the impact young people's involvement in an evaluation project can have on an organisation like NCB.

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A key text outlining a multi-method approach to seeking the views of very young children. See also other publications by Alison Clark and others at: http://www.ncb.org.uk/ecu_network/ycvn/ycvn_home/resources.aspx

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Grieg, A, Taylor, J and Mackay, T (2007) *Doing Research with Children*. Sage: London.

Useful introduction to undertaking a research project with children, including guidance on ethics and a focus on children as active research participants rather than as passive subjects of research. Outlines the main theories and approaches in doing research with children; different frameworks; and the unique nature of children as research subjects.

Tisdall, K, Davis, J and Gallagher, M (2009) *Researching with Children and Young People*. Sage: London.

Covers every stage of the process of doing a research project with children and young people, from ethics, research design and data collection through to analysis, writing up and dissemination. Includes top tips and case study examples.

Ethical research with children and young people (see also general resources above)

Alderson, P and Morrow, V (2011) *The Ethics of Research with Children and Young People: A practical handbook*. London: Sage.

This book is a useful source of information on relevant laws and guidelines, and on current debates in research ethics. It covers ethics at every stage of research and with all kinds of young research participants, particularly those who are vulnerable or neglected.

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Evaluation and impact

Mainey, A (2008) *Evaluating Participation Work: The toolkit and the guide*. London: Participation Works.

Guide to evaluating young people's involvement, and involving them in the evaluation process. The toolkit includes examples, tools and resources. This and other useful resources to support children and young people's participation can be found at: www.participationworks.org.uk/resources

Staley, K (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE.

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