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# A Guide to Actively Involving Young People in Research:

For researchers, research commissioners,  
and managers

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## About this guide

The guide was developed with a group of people – young people and older adults - who have been involved in research.

As the first stage, Perpetua Kirby (PK Research Consultancy) wrote an initial summary of literature on practice in this area. Following this, seventeen people took part in a workshop led by Perpetua and Roger Steel (INVOLVE) to discuss what should be included in the guide. The first draft was then written by Perpetua, with information on legal issues written by Maureen Winn-Oakley. This was discussed at a second workshop with the seventeen young people and young people's support workers. It was also sent out for comments to a wider group of researchers in the public health and social care field for their comment and input. The final draft was then amended by Perpetua and edited by Roger Steel.

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# 1.0 Introduction

## Key Points

- This guide is about why and how to actively involve young people (aged 12 to 21 years) as researchers within health and social care research.
- It is primarily aimed at researchers and commissioners of research.
- It is also written for professionals working with young people.
- We hope it will also be useful for young people and parents.
- The guide is designed so you can use it in different ways. You can either just read the relevant sections for you at the time or read it through from cover to cover.

## 1.1 What is this guide about?

This guide is about *why* and *how* to actively involve *young people* as researchers within health and social care research. It is about how to *actively involve* them, not as subjects of research and development, but as *partners* in the various stages of research, from commissioning, to evaluation and dissemination.

This guide aims to give researchers and commissioners of research working within the NHS, Social Care and Public Health some guidance on how best to involve young people in their work. We hope it will also be read by young people, as well as parents, teachers and other members of the public who want to support young people's involvement in research.

We think it will help professionals to meet article 12 of the UN Convention on the Rights of the Child (ratified by the UK in 1991) which asserts that children and young people should be involved in all decisions affecting their lives.

The guide is not an academic document, but draws on the experience of young researchers and older adult researchers, both through workshops and through related literature.

Many of the issues relevant to actively involving young people in research are similar to those for actively involving people in general. We recommend that you also read '**Involving the public in research and development in the NHS, Public Health and Social Care: Briefing Notes for Researchers**' by INVOLVE.<sup>2</sup>

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<sup>2</sup> Hanley, B. et al (2004) '**Involving the public in research and development in the NHS, Public Health and Social Care: Briefing Notes for Researchers**' INVOLVE

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## 1.2 Who are young people?

For the purposes of this booklet, we define young people as aged between 12 and 21. Much of the work involving young people in research includes those under 18 years of age, and some involves those under 16 years. As yet only a limited amount of work has involved younger children as researchers; there is some good practice in this area, but more scope for development. See section 8 for publications about involving children.

The young people who contributed to the guide were keen that we did not describe them as being other than adults because of the associated stigma of not being seen as useful members of society. For the purpose of this guide therefore, we have used the term 'older adults' when discerning between young people and their elders.

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## 1.3 What do we mean by research?

The Department of Health defines 'research' as work designed to provide new knowledge, whose findings are potentially of value to all, that is, generalisable. It defines 'development' as the testing and evaluation of new ways of doing things.<sup>3</sup> In other words, knowledge which has and can be tested so that it can be applied with confidence in all similar situations. Research can also be used to confirm or refute previous research findings.

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<sup>3</sup> From the **Strategic Framework for the use of NHS R&D Levy**. NHS Executive (1999)

## 2.0 What are the Benefits of Involving Young People?

### Key Points

There are numerous benefits to involving young people in undertaking research, including:

- Benefits to research and development (e.g. introduce young people's perspectives)
- Benefits to research dissemination (e.g. can help achieve bigger impact)
- Benefits to the young people who get involved (e.g. skills, valuable experience and recognition).

### 2.1 What are the benefits to research & development?

- Young people can identify research issues and questions that professional researchers may miss or not prioritise.
- They can help to ensure research tools (e.g. questionnaires, interview schedules, leaflets, reports etc) are worded in a language that is clear to their peers.
- Young people can offer a different perspective on what questions should be asked of respondents.
- Young interviewers may be able to help put their peers at ease in interviews, making the setting less formal.
- Young interviewees may open up more to their peers, depending on the topic and the skills of the young researcher. (At other times, they may prefer to talk with a clearly independent and older professional.)
- Researchers can develop their understanding of youth issues by working with young people and learn new skills for research.
- It can help researchers to stay mindful of young people's perspectives on the research agenda and process.

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### 2.2 What are the benefits to research dissemination and service development?

- When young people present research findings and share their own related experiences, this can have a greater impact on audiences.
- Involving young people in research projects can help bridge gaps between them and older adults. The research process offers new ways of engaging *with* young people, helping to overcome professionals' anxieties about

including them. It also highlights young people's competencies. This may help to push through change in organisational structures and cultures of participation.

- It can help to ensure practitioners are more accountable to young service users through accessing research that is more relevant to them.
  - Involving young people in research can be the beginning of an ongoing dialogue with them.
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## **2.3 What are the benefits to young people?**

- Participating in research is a way of enabling young people to be actively involved in issues affecting their own and their peers' lives.
- It can provide opportunities to contribute to their communities and services.
- Young people can gain recognition for their contribution (sometimes including payment).
- Taking part in research provides an active way to learn about services, citizenship and to gain a variety of skills.
- The experience may be life enhancing: helping with personal development, including increased confidence, self-esteem, and the belief that their views matter and can effect change.
- They also get to meet new people – both adults and peers - and it can be an enjoyable experience.
- It can add to young people's CVs for future employment.

## 3.0 When and How to Involve Young People

### Key Points

- There are numerous ways of involving young people in research.
- It is important to involve young people in deciding how they will be involved, and to ensure their participation is not token or manipulated by adults.
- Sometimes young people may be involved in just a few stages in the research, whereas in other projects they may be involved throughout the whole process.
- Young people can start being involved at any stage in the research but we recommend that you involve them as early as possible.
- There are different levels of involving young people in research; from consulting, to collaborating with them, to projects controlled by young people.
- The degree to which young people are involved will vary depending on the individuals themselves, the research purpose, and the available resources. These need to be considered carefully.

### 3.1 Ways of involving young people

There are numerous examples of different ways of involving young people in research. They can start being involved at any stage in the research, from identifying topics, prioritising and commissioning, through to planning, undertaking, evaluating and disseminating. We recommend that they should be involved as early as possible in the research 'cycle'. For example, it is unlikely young people will be motivated to help with dissemination if they were not involved with the research at the beginning. Take care not to assume that young people cannot be involved in certain stages or that they will want to be involved in them all. Ideally, ask them how and when they want to be involved before deciding.

Sometimes it may be more appropriate to involve young people in just a few stages, whereas in other contexts they may become involved throughout the process. This will depend on a combination of factors, including the research topic, the individuals' abilities, experiences and interests. Careful consideration is needed of all these factors when deciding how and when to involve young people. If the research topic is of sufficient interest to a group, for example, they may want to become actively involved in even the hardest analytical stages in order to understand more about the issue.

There are also different levels of involvement in research:

**Consultation** – When you consult with young people on research, you ask them for their views and use these views to inform your decision-making. For example, funders of research might hold one-off meetings with people who use services to ask them for their views on a research proposal. They will not necessarily adopt those young people’s views, but they may be influenced by them.

**Collaboration** – Collaboration involves active, on-going partnership with young people in research and the development of services. For example, young people might take part in a steering committee for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project.

**User-control** - User-controlled research might be broadly interpreted as research where the locus of power, initiative and subsequent decision making is with (in this case) young people, rather than with older adult researchers. It does not mean that young people undertake every stage of the research, or that ‘professional’ researchers are necessarily excluded from the process altogether. It is often the preferred, and sometimes the only legitimate research from the point of view of some service user groups. This is because they have become disillusioned with the mainstream research approaches which they have found to have disempowering effects on their lives.

## 3.2 Meaningful Involvement

Make sure that when you are planning to involve young people, their participation is not ‘token’ or manipulated by adults. With growing requirements for user involvement in research, there is a danger that young people’s participation could be undertaken simply as a tick box exercise. Meaningful involvement requires thought and consideration for those who will be involved to ensure they are able to usefully contribute to, and benefit from, the research process. If participation is done badly, this may have negative consequences, including cynicism from young people about the value of taking part in future initiatives.

Here are some questions to consider when planning meaningful participation:

- Is young people’s involvement planned from the beginning (rather than bringing them in at the last minute)?
- Are they involved in deciding how they want to get involved? Is participation always voluntary?
- Will they be supported to get involved in ways that suit their needs, abilities, interests, access needs, and availability, rather than expected to fit into adult structures?
- Will all information about the research be shared, so they are able to make informed opinions and decisions?
- Will their views be genuinely listened to, and influence decisions along with the views of other stakeholders?

- Will they be treated as equals? How will you demonstrate respect for their contribution?
  - How will they personally benefit from being involved?
  - Will disabled young people have the opportunity to contribute equally?
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### 3.3 Choosing an appropriate level of involvement

The degree to which young people are involved in research will vary depending on the individuals' choice and availability, the nature of the research, the accessibility of your approach, and the available resources.

**Young People:** Many young people are interested and willing to take part in research. The extent to which they want to and are able to participate will vary. Some feel that they should be involved at all levels in all research, whereas others want to limit their involvement and some do not want to get involved at all. Some young people can become bored within research processes that are long and technical. Those who feel the research may expose their lack of literacy and numeracy may be particularly reluctant to take part. Those experiencing a level of chaos in the rest of their lives can be hard to keep in touch with and have different timetables to professionals. Many young people however, demonstrate huge commitment and give up large amounts of their time to contribute to research projects.

Assess what impacts the expected research tasks are likely to have on the young people you wish to involve. Are the tasks likely to cause them undue stress or feelings of failure, or improve self esteem and open up opportunities to be 'stretched'? This needs to take account of their age, ability, availability and interests. Ask them which research tasks they feel comfortable with and able to handle.

Take care not to make assumptions about what young people and children can or cannot do, but assess this, if possible by consultation with them. If some research tasks are difficult, consider ways of involving them in other stages of the research, rather than excluding them altogether. Consider how to make the research more accessible and how willing you are to adapt it, so that young people can get involved in parts or all of the research. Think about whether it would be possible to train some to do more skilled tasks. Perhaps involve different young people in the various stages; they do not all have to do the same thing. Be flexible and creative about how they can get involved.

Some stages in the research may be less appealing for young people than others. For example, it may be particularly challenging for some young people to participate in the analysis and write up, which can be technical, time-consuming, difficult and boring. However, they may want to have some input into interpreting the data and commenting on researchers' analysis. Sometimes it *may* also be inappropriate to involve young people in certain stages: for example, undertaking fieldwork in research on some particularly sensitive subjects and some topics may be inappropriate for younger children (e.g. sexual health).

**Purpose of research:** It is helpful to be clear about why you are involving young people. Some research projects may choose to prioritise the process of involving them as an end in itself: enabling them to express their views, for their 'empowerment' and development. Others will be most concerned with ensuring the robustness of the research in order to use the findings to influence change more widely. The extent to which different aims are prioritised will have some impact on the ways in which young people are involved.

**Resources:** All participatory research projects (whether with older adults or young people) need the time and resources to support participation. This is easy to underestimate. Time is needed to contact and recruit young people, and to support them in contributing at different stages of the research. Support workers are likely to be needed to work closely with young people too (see Section 6). Young people's schedules are often very different to those of older adults, and so flexibility will be needed for contact with them at different times. For example, working around school and schoolwork, holidays and 'social' time. Travel and location can also be very important considerations when working with young people, and resources need to be put in place accordingly. Some young people may have carers, or personal assistants (pa's) perhaps because they have a long-term medical condition or are disabled. The additional expenses involved will need to be taken into account.

## 4.0 What are the Power Issues when Involving Young Researchers?

### Key Points

- Involving young people in research can help redress power imbalances between younger and older people and build new, more positive, relationships.
- Both younger people and older adults have something to bring to the research process and something to learn from each other.
- When involving young people their views need to be listened to, respected, taken into account, and used to inform the research process and outcomes.
- It is valuable to think about the different areas of power that young people and researchers have within research, and to redress these where appropriate.

Involving young people in research can fundamentally help redress power imbalances between researchers and the researched, and between older adults and younger people. Other inequalities can also be challenged by involving more marginalized groups of young people. For their involvement to be a positive experience there needs to be an enabling environment and culture in which they are in a power-sharing role. This is about building and creating new relationships in which everyone's input is welcomed, respected and considered valid.

Young people may not have in-depth knowledge about research issues and methods, although some will have experience and skills in this area. Older people do not have in-depth knowledge about what it is like to be young today. Young people have knowledge about how it feels to be researched, talked to by older adults, or may have personal experience related to the research topic. This can help to ensure the appropriate design of research related to young people's lives (not just on specific youth issues, such as education and leisure, but also for community issues that impact on young people's lives, such as transport, regeneration and health).

Together support workers and young people can negotiate and build upon their different experience, knowledge, skills and perspectives to develop a research project that incorporates diversity. This requires that both come with positive attitudes about each other and the issues under discussion. Adults can learn from young people, and vice versa.

Frequently young people are asked their opinions, but their views are not always acted upon. Where they are involved, it is important to take their views into account, although this does not mean they have to be responsible for making all final decisions. By the end of the research young people need to know how they

have played a role in creating real change. Where it is not possible or appropriate to act on what they say, it is important to explain why.

It is valuable to consider and acknowledge the different areas of power that young people and researchers have within research, and to redress imbalances, where appropriate, to ensure adults do not impose on younger people, and also to ensure that involved young people do not impose on their peers. Power is frequently asserted by excluding young people from making decisions within research. It can also be imposed in more ingrained and subtle ways of talking and being with young people which can be hard to overcome, yet can have very negative effects. This includes using unintelligible or patronising language, using inappropriate body language, using physical space in a particular way (e.g. seating arrangements), using adult-preferred structures (e.g. formal meetings), not giving age-appropriate information and feedback, and by giving adult concerns priority. Young people also assert their power, for example, by deciding whether or not to participate in research and choosing what to reveal and what to withhold. In addition, they can assert power over those they research; their status changes when they become researchers.

When thinking about power within research, here are some questions to consider:

- Who decides what will be researched?
- Who pays for the research?
- Who decides how research information will be used?
- Who decides how young people will be involved?
- What information is communicated to young people?
- What power do those being researched have?
- Who benefits from the research?
- To what extent is it possible to redress power imbalances?
- When is this appropriate and when is it not?

## 5.0 How to Identify and Support Young People to Get Involved

### Key Points

- Local and national organisations may be able to help access young people.
- You may want to recruit a new group or access an established group of young people; there are advantages to both approaches.

Some initial sources for accessing young people include:

- Local youth organisations, including the Youth Service.
- National youth organisations including:
  - **Barnardo's** ([www.barnardos.org.uk](http://www.barnardos.org.uk))
  - **British Youth Council** ([www.byc.org.uk](http://www.byc.org.uk))
  - **Children's Society** ([www.the-childrens-society.org.uk](http://www.the-childrens-society.org.uk))
  - **Carnegie Young People's Initiative** ([www.carnegie-youth.org.uk](http://www.carnegie-youth.org.uk))
  - **National Children's Bureau** ([www.ncb.org.uk](http://www.ncb.org.uk))
  - **National Youth Agency** ([www.nya.org.uk](http://www.nya.org.uk))
  - **Save the Children** ([www.savethechildren.org.uk](http://www.savethechildren.org.uk)).
- Schools, colleges and universities.

You may want to recruit a new group of young people to participate in the research or access an existing group through a youth agency (or other organisation):

- Recruiting a new group ensures that a range of young people have the opportunity to participate, but it may take a considerable amount of time to outreach and make contact with people in different organisations.
- Involving an existing youth group saves time in recruitment and building group cohesion, but limits participation to just one group. Established groups are sometimes consulted time and again, so it may be worth thinking about whether other young people could also be given an opportunity to get involved.

Information about the project, presented in clear and accessible language, will be needed for those who might be interested in getting involved. A 'job' or 'volunteer description' and agreement are often used to ensure involvement is clearly defined. This includes expected roles, time commitment, and how they will be supported and reimbursed.

When deciding how to involve young people try to ensure enough flexibility to accommodate their lifestyles and availability. Hold meetings in the evenings, weekends or during the school holidays. Ensure venues are accessible and individual support needs are catered for. Be prepared that young people's

attendance and punctuality may vary. If this is going to be a problem, stress this well in advance.

There can sometimes be difficulties in keeping young people on board with a research project. Some may have other commitments (such as school, college or university) or leave for other reasons. It may be necessary to allow for drop out by recruiting more young people at the start of the project, or to recruit more over time. Also allow for some people to leave and to return at a later date.

## 6.0 Supporting Young People's Involvement: the Role of Support Workers

### Key Points

Support workers play a highly active role in enabling young people to participate meaningfully in research. Involve those with experience of working with this age group.

The types of support to provide include:

- Facilitating young people's involvement, including offering group and individual support.
- Advocating between young people and other professionals, organisations and community members.
- Organising and administering meetings.
- Providing research preparation and training.
- Making research interesting, accessible and engaging.
- Demonstrating that young people's contributions are valued.
- Providing feedback on research findings and how the research is being used to improve things for young people.
- Developing an exit strategy so that young people can continue to be supported, if requested and possible.
- Evaluating young people's involvement in the research.

Support workers play a highly active support role in enabling young people to participate meaningfully in research. It is important to involve researchers or other workers skilled in working with younger people, who are able to demonstrate respect and appropriate levels of sensitivity to their needs. If workers do not already have relevant experience and skills, then it may be appropriate for them to undertake training or work alongside more experienced workers. Alternatively, involve partner youth agencies with relevant skills and the capacity to support young people over time. Involving young people in recruiting and selecting support workers (and partner agencies) will help to ensure they are able to communicate and get on well with them.

We explore the different roles required by support workers:

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## 6.1 Facilitation

The support workers' role is to 'facilitate' rather than direct young people's involvement in research. This includes planning for young people to engage in ways that suit their abilities, interests, time availability, access needs, and the research context. Also providing sufficient structure and support to ensure their time on the project is beneficial to them and the research process. This includes group support to establish and maintain group cohesion, and also assistance to individuals depending on their specific needs. This may include advice and assistance with personal issues (e.g. benefits, housing crisis) or referring young people to those who can provide this support [see Appendix 1 on information relevant to employing young people, including information on payment and welfare benefits]. Try to remain flexible so that they can identify ways in which they want to be involved and supported.

Young people expect facilitators to be:

- Non-judgemental
- Friendly and approachable
- Unbiased
- Good at communication and not patronising
- Willing to learn/gain skills
- Open minded and prepared to be challenged

Young people also expect facilitators to:

- Maintain confidentiality
- Help to establish and maintain 'ground rules' in meetings
- Know how to identify and use young people's skills
- Give appropriate direction – rather than force ideas - and provide young people with necessary information
- Value and acknowledge young people's contribution.

When discussing research ideas support workers can act as a sounding board, provide information and share their own ideas. It is important for young people and older adults to be willing and able to engage in dialogue in which both discuss their own and others' views and experiences. For this to be meaningful, workers need to support young people in challenging power imbalances and ensure respect for their contribution. This does not mean they have to agree with everything they say or want. Young people also have to acknowledge workers' experience and respect their views. The facilitator's skill lies in supporting young people's engagement in discussion together with peers and with adults, to enable different views to be expressed, to encourage critical thinking and to establish agreed plans of action.

Some young people, particularly those with little or no experience of being consulted, may need some additional initial support to prepare them to be able to participate. This might include developing confidence to share their views in a group, informing them of any relevant background, and some more time to get to know and develop positive relationships with other young people and workers.

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## 6.2 Advocate

Workers often need to act as a link between the young people and other professionals, organisations and community members, helping to make contact and advocate on their behalf:

- Young people may not be taken seriously by professionals. For example, participatory youth research may be rejected by Research Ethics Committees, or 'gate-keepers' may not allow young people to access their service users for the research. Workers can help to promote the research and respond to professional concerns.
- Workers can ensure research is disseminated to key decision makers and help to ensure the findings are listened to and acted upon. Youth-led recommendations may make service providers defensive, so workers play a key role in establishing dialogue and resolving conflict between young people and decision makers.
- Workers can ensure participants receive feedback about the outcomes from the research.

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## 6.3 Administration

Support workers usually take on responsibility for organising and administering meetings, including booking venues, paying expenses and wages (where relevant) and typing up notes. Young people may choose to take on some of these roles, but frequently do not have sufficient time to do so. As many are at school or college during the day they also have restrictions on what they can do during office hours. Workers may need to ensure young people have easy access to meetings, particularly when working with disabled young people, and ensure that transport is arranged where appropriate.

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## 6.4 Research Preparation and Training

The Department of Health's Research Governance Framework<sup>4</sup> specifies the need for quality research, including where students or new researchers are involved. The principal investigators are responsible for ensuring young people have adequate supervision, support and training to maintain research integrity and standards. Workers may play a key role in shaping the research, while also involving young people in influencing its design. Young people will need appropriate and sufficient information to make informed decisions. Workers may need to inform them about research theory and practice, making this comprehensible and relevant to each research context.

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<sup>4</sup> Department of Health (2001) '**Research Governance Framework for Health and Social Care**' ([www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment](http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment))

It is important to prepare young people so that they can contribute fully to the research. The type of support offered would need to vary depending on how they get involved. This might include:

- Information about how and why the research is being undertaken, and discussion about what research is.
- The importance of equal opportunities, respecting other people's views and informed consent.
- Identifying research questions.
- Training on how to conduct interviews, including discussion of what makes a good (and bad) interview, listening and communication skills, and plenty of role-play practice.
- Safety and ethical issues including the importance of confidentiality and anonymity, and how to deal with disclosure of child protection issues (see section 7.0 for further details on health, safety and well-being issues).

Please refer to recent research into training for public involvement in research.<sup>5</sup>

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## 6.5 Interesting and Enjoyable

Making research enjoyable and engaging helps to ensure participants' experiences are positive, increases motivation and builds social cohesion within groups. Workers need to think how they can be interesting to young people as well as interested in what they say. Putting in this effort demonstrates the value you have for their contribution. This is particularly important if young people are giving up their time voluntarily. Here are some suggestions:

- Involve young people in deciding how to make the research more engaging.
  - Ensure the tasks are appropriate for the age, interests and capabilities of the participants.
  - Ensure meetings are not too formal; keep them quick moving and active.
  - Keep written information short and clear.
  - Keep meetings short and/or have plenty of breaks.
  - Provide food and drinks (but do not assume the type of food that young people will want – check with them first if possible).
  - Organise enjoyable and social activities such as trips out.
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## 6.6 Valuing Contributions

Young people's contribution to research needs to be recognised to ensure they know their input is valued. This includes valuing the time they give to research. We consider paying all expenses as the minimum baseline. In addition, there are a number of ways that their contribution can be recognised both informally and formally.

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<sup>5</sup> Lockey, R. et al (2004) '**Training for service user involvement in health and social care research: a study of training provision and participants' experiences (The TRUE Project).**' Worthing: Worthing and Southlands Hospitals NHS Trust.

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Informally:

- Keep the research process flexible enough to involve young people in ways that suit their abilities, interests and availability.
- Actively listen and demonstrate you are listening.
- Check your notes with young people to ensure you have accurately recorded their ideas.
- Respond to ideas.

Formally:

- Accreditation.
- Certificate of achievement.
- Letter of reference and thanks.
- Acknowledgment or joint authorship in the research report.
- Voucher of young people's choice.
- Honorarium payment or wage. [See Appendix 1]
- Fun and social activities, such as a trip (e.g. bowling) or a meal out.

The form of recognition will vary depending on a number of factors, including the age, level and type of involvement. Each situation is different; consulting young people about how they want to be recognised can help to decide the most appropriate method. Payments for expertise and time are considered best practice although the rates and type may vary. [See section Appendix 1 for more information on 'Payment and Benefits']

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## 6.7 Feedback on outcomes

It is important that research participants – both the subjects of research and those undertaking or advising research - see the outcomes of their input. From the very beginning of their involvement they need to be informed and clear about how their information is to be used. Increasingly young people are asked their views – through research or other consultations – but too frequently they do not influence decisions made by adults. It is important to ensure their views are taken into account and to give feedback on how they have made a difference, including feedback on:

- **Research outputs** - as a minimum we recommend giving young people summaries, and easy access to full research reports if they want them, written in an accessible language and/or other outputs such as videos, posters or tapes detailing the research findings.
- **Research outcomes** – in addition we strongly advise including information on how the research is being disseminated, how the findings are being used to improve things for young people and what changes have been achieved to date. If no change has happened then the reasons why can be explained to young people.

A feedback event is recommended as it provides a good opportunity for young people, workers and others to engage in discussion about how the research information can be used. It may be possible to arrange for young people to meet with the decision makers who will use the research to plan services and policies.

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Feedback can be given at an informal meeting or through more formal activities including presentations, workshops or conferences.

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## **6.8 Exit Strategy**

It is important to make provision for support for young people at the end of a research project, and if someone leaves part of the way through. Young people involved in research often want to continue meeting as a group and to work on issues explored in the research. We therefore recommend developing an exit strategy, especially if they have had long-term involvement, to plan how they could be supported to continue meeting (possibly involving another agency) or to prepare them in advance for the end of the project. Accessing groups of young people that are being supported by existing agencies helps overcome this potential difficulty. This also makes it easier to access the group after the end of research to give feedback.

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## **6.9 Evaluate Youth Participation**

Young people can be involved in evaluating how the research process worked, in order to learn and improve future practice. Workers or young people can facilitate a discussion on the process. Also providing anonymous opportunities (e.g. using questionnaires) may make it easier for young people to be open and honest. Another approach would be to involve another group of young people to peer review the research process and outcomes.

Possible evaluation questions might include:

- Is the research process empowering or disempowering: a) for the young people undertaking research, and b) for the young respondents?
- How have young people contributed to the research process and to what extent has this benefited or compromised the quality (e.g. reliability and validity) of the research?
- What have workers/researchers gained from involving young people? Has it led to on-going changes in research practice?
- Have the research findings had an impact on policies and practice for young people? Did their involvement in the research contribute to these changes?

## 7.0 Ensuring Young People's Health, Safety and Well-Being

### Key Points

There are some health, safety and well-being issues specific to involving young people in conducting research that need to be addressed:

- It is important to ensure all participating young people's safety, including those doing research and those being researched. Involve young people in deciding how to ensure their well-being.
- Safety precautions include: training young people in child protection issues, police checks, ensuring safe locations and using mobile phones.
- Recognise research may impact on emotional well-being, assess this risk and offer appropriate support where necessary.
- It is important to gain informed consent from all young people.

The following issues need to be considered when planning for the health, safety and well being of young people to be actively involved in research.

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### 7.1 Safety issues during fieldwork

It is important to talk through with young people (during initial training and throughout the process) about safety issues involved in undertaking research, so that they are well prepared to ensure their own safety and that of others.

This includes ensuring the safety of any young people being researched. Being careful not to assume that they will want to talk with peer interviewers and taking care that no peer pressure is exerted on them to participate. Ensuring young researchers have sufficient understanding of consent, confidentiality and anonymity issues, and the necessary research skills to apply these, should help to ensure they act appropriately with interviewees.

We recommend a number of specific safety precautions that should be considered if young people are undertaking fieldwork, to protect their own and others' safety [also see the section on 'Ensuring the safety of young employees' in Appendix 1 for more information]:

### ***Before the Visits***

- Young researchers can be trained in child protection issues<sup>6</sup>, including how to explain this to other young people and what to do where information of a legally sensitive nature is disclosed.
- As with all adult researchers, young researchers who may come into contact with other young people and children in the course of their work, will need to be police checked. Children as young as 10 years may be checked.

### ***Arranging visits***

- Young people undertaking fieldwork pre-arrange visits so that workers know of their whereabouts.
- Ensure they are contactable at all times (e.g. use a mobile phone, arrange specific meeting points).
- Ideally, encourage young people to work in pairs (or teams).
- When meeting with other young people carry proof of identity and proof that they represent the organisation.
- Ensure those being visited are aware that the young people are coming, have confirmed it is convenient, and have had time to check them out.

### ***Safe Meeting Places***

- Young people need to be careful not to meet others in places where either could feel or be vulnerable (e.g. alone in bedrooms).
- Arrange to meet others in public places rather than homes, if possible.
- If visiting homes try to ensure that carers or parents are in the property, but not necessarily in the same room or perhaps arrange interviews where they can be seen but not overheard.
- Young researchers need to ensure that respondents, particularly other young people, have input and feel comfortable about the meeting, time and choice of venue.

### ***Emotional Well-being***

Young people conducting interviews, especially when interviewing others with similar personal experience, may get emotionally involved in the issue, find it hard to deal with themes brought up for themselves, and may feel frustrated at not being able to help the interviewees more. The impact of research interviews on both the interviewer and interviewee needs to be monitored and professional support provided if necessary.

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## **7.2 Gaining consent**

The process of gaining consent from young people to become actively involved in research projects as researchers varies, depending on the age of the young person.

- Older young people (18+) are able to give their own consent without their parents' agreement.

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<sup>6</sup> The Protection of Children Act 1999: 'A Practical Guide to the Act for All Organisations Working With Children' Department of Health

- Those under 18 who have sufficient understanding to be able to make up their own mind in decisions may be deemed competent (under the Gillick ruling<sup>7</sup>) and therefore able to give their own consent.
- It is considered good practice, however, for parental/carer consent to be gained for all young people under 18, particularly if they are to meet without workers already known to them, if they are to meet regularly, if they are required to travel some way from home (e.g. to another town) or if they are staying away from home for any reason. Also, a contact name and details are needed in case of an emergency.

All young people need to be given sufficient and accessible information about what their involvement will mean so that they can give informed consent. They need to be told they can withdraw consent at any time, without explanation, or impact on how they are treated.

Young people must also be trained to obtain consent from research participants. They do not always feel they should have to seek the consent of adults to interview children or other young people so it is important that they understand the legal position. Research participants may be Gillick competent for one study, but not another, depending on the details of the study.

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<sup>7</sup> The **Gillick ruling (1984)** established the principle that in the absence of an expressed statutory rule, all parental authority ‘yields to the child’s right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision’.

## 8.0 Useful Publications

Clark, J., Dyson, A., Meagher, N., Robson, E., and Wootten, M. (eds) (2001) **Young people as researchers: Possibilities, problems and politics**. Leicester: National Youth Work Press.

Fielding, M. and Bragg, S. (2003) **Students as Researchers: Making a Difference** Cambridge: Pearsons.

France, A. (2000) **Youth researching youth: the triumph and success research project**. York: Joseph Rowntree Foundation.

Kirby, P. Lanyon, C. Cronin, K. Sinclair, R. (2003) **Building a Culture of Participation: Involving children and young people in policy, service planning, delivery and evaluation.** (Report and Handbook) Department for Education & Science

Kirby, P. (1999) **Involving Young Researchers: how to enable young people to design and conduct research**. York: Joseph Rowntree Foundation.

Hanley, B. et al (2004) **Involving the Public in Research and Development in the NHS, Public Health and Social Care: Briefing notes for researchers**. INVOLVE

Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J. (2004) **Training for service user involvement in health and social care research: a study of training provision and participants' experiences (The TRUE Project)**. Worthing: Worthing and Southlands Hospitals NHS Trust.

Morris, J, (1998) **Don't leave us out: Involving disabled children and young people with communication impairments**. Joseph Rowntree Foundation

Steel, R. (2003) **A Guide to paying members of the public actively involved in research**. INVOLVE

Steel, R. (2003) **Consultation Document for Involving Marginalised and Vulnerable Groups in Research**. INVOLVE

Ward, L. (1997) **Seen and Heard: Involving disabled children and young people in research and development projects**. Joseph Rowntree Foundation

Worrel, S. (2000) **Young People as researchers, a learning resource pack**. London: Save the Children.

## APPENDIX 1:

### Specific information on employing young people

Under the Research Governance Framework for Health and Social Care 2001<sup>8</sup>, all individuals engaged in research projects which fall within its remit, whether volunteers or not, require an 'honorary contract' so that the sponsoring organisation (who is taking overall responsibility for the research, e.g. NHS Trust, Local Authority, University), can meet its obligations to ensure the health and safety of all involved in the research and cover any liability. If you are not sure whether your project falls within the remit of the Research Governance Framework you can check with COREC<sup>9</sup> or your local Research and Development Support Unit.

Research projects not subject to Research Governance should in any case ensure that liabilities of young volunteers are adequately covered and that they are adequately equipped and informed on health and safety issues. If young people are given cash as an 'honarium' payment they can technically become employees, albeit casual workers. Thus Health and Safety and Employment legislation would have to be applied. The relevant legislation is summarised below.

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#### Contracts

A minor's contract of employment (agreed verbally or signed written) is binding providing that, on the whole, the contract is for the benefit of the minor. (Issues of consent apply – see Section 7.2)

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#### Children of compulsory school age

Turning 16 does not automatically mean a young person is able to work full time. They are considered to be of compulsory school age until the last Friday in June of the school year in which they reach their 16<sup>th</sup> birthday. For these young people the following rules apply:

- If a young person of school age is seeking employment then the employer needs to register such work with the local educational welfare officer. Both employer and employee are registered. Forms will need to be completed and consent sought from parents and from the school. It is possible that schools may not consent to a young person undertaking such work if the young person's attendance at school is already below average. Failing to register may invalidate an employer's insurance policy.

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<sup>8</sup> **Research Governance Framework for Health and Social Care 2001** - Department of Health

<sup>9</sup> Central Office of Research Ethics Committees. Website: [www.corec.org.uk](http://www.corec.org.uk) Tel: 020 7725 3431.

- Children are only allowed to work as long as it does not interfere with their education, health and physical development.
- There are time restrictions on how long 15-16 year olds still subject to compulsory schooling can work. This includes a maximum of 12 hours per school week during term time (no more than 2 hours a day), plus 8 hours on a Saturday and 2 hours on a Sunday (flexibility is needed in respect of some religions having different religious days).
- In school holidays they can work up to 8 hours a day/35 hours per week, but should have 2 consecutive weeks where there is no employment.
- They should have a 1-hour rest break after 4 hours.
- No child of compulsory school age can work before 7 am or after 7 pm.
- Children under the age of 14 years generally may not work, although some local byelaws allow children of 13 to do some kinds of work. There can be local differences around whether a young person can contract to work at 13 or 14. Some local authorities provide guidance for working at 13. (Contact the local council's Child Employment Officer for details of local byelaws)
- This does not mean people under 14 should be excluded, but as volunteers different arrangements should be made for them in terms of insurance, health and safety, and covering expenses. (See 'Payments and Benefits' later in this appendix.)

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## **Young people aged 15-17 years old no longer subject to compulsory schooling**

- The Dept of Trade and Industry (DTI) has published draft regulations for implementing the remainder of the EU Young Workers Directive. (No actual date fixed for this but due to be implemented in the near future.) These will limit the working time of young workers to 8 hours a day or 40 hours a week (there are some exclusions). Night work is prohibited (some exclusions). There are provisions for young workers to be adequately supervised.
- Rights to rest periods –12 hours rest in every 24 hours (unless day's work split/short duration), 48 hours rest in every 7-day period. Special exclusions possible e.g. if no adult available to do work, if work temporary and needs to be done at once. Workers' rights to rest break of 30 minutes after 4hours 30mins work (special exclusions e.g. if can't measure work).

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## **Work for those 18 + years**

- A 48 hour week is stipulated for all adults, although there is no actual rule that hours of work cannot exceed 48 in a week. Employers must take all reasonable steps to ensure that a worker's working time, including overtime, does not exceed an average of 48 hours for each seven days in any reference period of 17 weeks (extensions in special cases).

- Over 18 adult rights to rest periods - 11 hours rest in every 24 hours, not less than 24 hours rest in every 7-day period. However this does not apply where worker's working time cannot be measured/determined. Adult rights to rest breaks whilst working are 20 minutes after six hours work (special exclusions e.g. if can't measure work).

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## Payment and benefits

[See section 6.6 of this report for discussion on recognising young people's contribution, including payment]

Young people over the age of 16 years, and no longer subject to compulsory education, will be given a National Insurance number enabling them to take up employment. National Insurance contributions are based upon the amount of earnings. Children under 16 do not pay National Insurance.

There is a National Minimum Wage rate which applies to workers between 18 to 21. From October 1<sup>st</sup> 2004 there is a new National Minimum Wage rate for workers under 18. This applies to 16 and 17 year olds (above compulsory school leaving age). The full minimum wage rate applies to workers aged 22 or above. (To find out what the current minimum wage rates are set at, see contact details for the DTI in Appendix 2).

The rates apply to the broader term of 'worker', encompassing, for example, home workers, agency workers etc., rather than a narrow definition of employee. While it is legal to pay young people less than adults, where they have specialist skills, for example the ability to establish good rapport with peers, this should be recognised in the rate of pay as it would be with adults.

Some organisations pay young people an honorarium payment for their time (from about £10 to £50 a day in addition to expenses). If under 14, regulations say that this work is not counted as 'being employed' in the sense that the young person is not taxable, as they will probably not be earning enough to pay tax. For this reason, employers do have discretion on how they treat small cash payments to such young people. It may also be possible to acknowledge their efforts by giving them vouchers, or mobile phone top up cards, for example.

Young people aged 15 to 16 no longer subject to compulsory schooling may be in receipt of benefits (e.g. Benefits for Care Leavers). The payment young people receive from employment may affect their benefits. The onus is on the young person to declare such income, but the employer could provide a short written statement generally to all young people, reminding them of the need to declare such income if in receipt of benefits. If a child is registered to attend school, their earnings from a part-time job will not affect any state benefits that their parents/guardians receive.

For further guidance on payment see: ***'A guide to paying members of the public who are actively involved in research'*** published by INVOLVE.<sup>10</sup>

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<sup>10</sup> Steel, R. (2003) 'A guide to paying members of the public who are actively involved in research: For researchers and research commissioners' INVOLVE

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## **Ensuring the safety of young employees**

[See section 7.1 of the report for discussion on ensuring young people's health, safety and well-being]

There is a legal duty on employers to safeguard the physical and mental well-being of employees whether adults or young people. Employers will need to be especially mindful of such issues where workers are young.

Employers have a duty to ensure the health, safety and welfare of workers even when not on their premises. All employees must be properly trained and given advice concerning safety matters so that they can be aware of their own safety and the safety of others (particularly other young people). This is particularly pertinent to young workers. Employees also have a duty to take reasonable care of themselves when at work or on work business elsewhere and to be aware of the safety of others.

When workers are young people, employers must carry out risk assessments and inform parents (or those with parental responsibility) of any particular risks to their children, and the measures taken to remove or reduce risks. In carrying out risk assessments, employers must take into account the child's level of maturity and experience.

Employers must insure young people against accidents and injuries incurred whilst carrying out their work. Failure to insure workers is a criminal offence and employers can be prosecuted.

Child workers should have suitable clothing and outdoor protection from inclement weather. Employers should provide luminous/fluorescent/reflective clothing where relevant. Other suggestions include the provision of torches and alarms and making young workers aware of other dangers. There is a Highway Code written specifically for young people that can be obtained from the Divisional Road Safety Officer.

Young workers should not be expected to carry excessively heavy loads. All injuries to employed persons need to be recorded and reported as appropriate. Young workers need to be aware that they should report such injuries.

## Appendix 2:

### Useful Contacts and Resources on Employment

#### Police Checks

For further information contact the Criminal Records Bureau (CRB) tel: 0870 90 90 844 or website: [www.disclosure.gov.uk](http://www.disclosure.gov.uk). For relevant legislation see: The Police Act 1997 and The Protection of Children Act 2000.

#### Employment

Guidance to the Working Time Regulations 1998 (WTRs), whose origins are in the EU Young Workers Directive 93/104, can be found in *A Guide To the Working Time Regulations* issued by the DTI in 1998 (updated 2000). It is also available on website [www.dti.gov.uk/er](http://www.dti.gov.uk/er)

#### Information on Current National Minimum Wage rates

For further information including up to date information on wage rates contact the Employers Helpline tel: 08457 143 143. See department of Trade and Industry website: [www.dti.gov.uk/er/nmw/](http://www.dti.gov.uk/er/nmw/) , or Helpline 0845 6000 678.

**Information on National Insurance** contributions is available from the Employers Helpline on tel: 08457 143 143.

**Advisory Conciliation and Arbitration Service (ACAS)** provide information and advice on employment matters, including working hours. Website [www.acas.org.uk](http://www.acas.org.uk)

**Relevant health and safety legislation** includes the Health and Safety at Work Act 1974, The Workplace (Health Safety and Welfare) Regulations 1992, European Community Regulations, Working Time Regulations. See the Health and Safety Commission website: [www.hse.gov.uk](http://www.hse.gov.uk)

For information on insurance issues contact the Health and Safety Executive on tel: 08701 545 500.

#### Welfare Benefits

Details about Social Security Benefits and payments to young people are available from Dept of Work and Pensions: [www.dwp.gov.uk](http://www.dwp.gov.uk)

## APPENDIX 3:

### About 'INVOLVE' and the Support Unit

The Director of Research & Development in the Department of Health set up Consumers in NHS Research<sup>11</sup> in 1996. In 2003 this Group was renamed 'INVOLVE' so that it better reflected an extended remit beyond the NHS to include the Policy Research Programme (PRP). The PRP is concerned with social care and public health research.

The 'INVOLVE' Group aims to ensure that people's involvement in research and development improves the way that research is prioritised, commissioned, undertaken and disseminated. We believe that the involvement of people who use services in the research process leads to research that is more relevant to people in general and more likely to be used. If research reflects the needs and views of the 'end user', it is more likely to produce results that can be used to improve practice in health and social care. The INVOLVE Group is supported by a Support Unit – a small team based in Eastleigh in Hampshire. The team is employed by the University of Leeds under the National Cancer Research Network.

#### The Support Unit:

- provides information, advice, and support to members of the public, researchers and those working within the NHS research programmes and the Policy Research Programme (PRP).
- gives practical support for the work of the INVOLVE Group
- produces publications on the involvement of people who use services in research
- runs a website
- maintains a public database of research projects which involve or have involved people who use services
- organises seminars, workshops and conferences on public involvement in research

If you would like more information on our work, please contact the Support Unit:

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Website: [www.invo.org.uk](http://www.invo.org.uk)

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<sup>11</sup> Originally the Standing Group on Consumer Involvement in the NHS Research and Development Programme

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