NIHR | School for Public Health Research

Strategy for engaging and working with children and young people

NIHR SPHR Children, Young People and Families Programme:

Enabling children and young people's involvement in whole system action to reduce inequalities in the social determinants of health

NIHR | School for Public Health Research

Developed by:

Eleanor Holding, Mary Crowder, Hannah Fairbrother, Naomi Griffin, Nicholas Woodrow

in association with

ayph | Association for Young People's Health

and

CHILYPEP
CHILDREN AND YOUNG PEOPLE'S EMPOWERMENT PROJECT

May 2021

Purpose of the strategy

This strategy has been written to support the work of the SPHR Children, Young People and Families (CYP&F) Programme Phase 2 project - Enabling children and young people's involvement in whole system action to reduce inequalities in the social determinants of health. This project will explore children and young people's views of health and use the findings to inform the development of a toolkit to enable CYP to take action to reduce health inequalities. The strategy is intended to inform a coherent approach to working with CYP across all elements of the project (including public involvement and engagement [PI&E], data collection and toolkit development). These overarching principles will be used within the project alongside relevant safeguarding procedures and other related policies. Our principles for working with CYP will be under constant review as the project progresses. Although the guidance has been developed for specific use within the above project, it has potential relevance for other projects involving CYP across the SPHR programme.

How the strategy was developed

Our principles for engaging and working with CYP have been developed through the bringing together of guidelines from INVOLVE and our community partners; the Children and Young People's Empowerment project (Chilypep) and the Association for Young People's Health (AYPH).

INVOLVE

INVOLVE is the UK's participation charity which aims to put people at the heart of decision making. INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. For more information please see the INVOLVE website: https://www.invo.org.uk

The Children and Young People's Empowerment (Chilypep) project

Chilypep is an established partner for the SPHR CYP programme and has helped facilitate data collection and PI&E for previous projects. They will continue as a partner on the current project and will assist with data collection, PI&E and the piloting of methods. Chilypep is a charity dedicated to raising the voices of young people to build resilience and confidence and to provide a platform for influence. They particularly work with CYP from disadvantaged backgrounds in Sheffield and Barnsley.
For more information please see the Chilypep website: https://www.chilypep.org.uk

Association for Young People's Health (AYPH)

AYPH is a partner within the project and they will have particular responsibility for delivering workshops in relation to the toolkit. AYPH is a national organisation which provides an independent voice for young people's health. AYPH works to improve the health of 10-24 year olds. They bridge the worlds of policy, practice and evidence to promote better understanding of young people's health needs, and to advocate for youth friendly health services. For more information please see the AYPH website: https://www.youngpeopleshealth.org.uk/about-us

Our approach to working with CYP will adhere to the guidelines of each of these organisations which have themselves been informed by the review of existing guidelines and CYP involvement. The guidelines relate to work with CYP aged 10-25 specifically.

Our principles for engaging and working with CYP

Timing and location:

- CYP have busy lives and need to be given enough time and information to fully consider their involvement in the suggested activity. We will give a minimum of two weeks' notice before involvement in any research activities.
- We will be flexible around when and where we meet CYP, acknowledging that they generally cannot meet during school or college times. We will aim to organise meetings at times and locations which are convenient for CYP.

Communication and language:

- It is important that we do not make assumptions about what is important to CYP or what they are capable of – they are active participants in the research and their opinions should be respected.
- We will present information to CYP in an accessible way– and avoid using jargon, academic phrases or patronising language
- We will explore multiple ways of communicating with CYP, such as via the telephone, video call, email, social media and workshops.

- We understand that circumstances and interests may change and it may not always be possible for CYP to attend each research activity. We will reassure CYP who are unable to attend and will provide information on what happened after the event.
- We will keep CYP informed about the results of the research and what happens afterwards – it is important that they understand what their involvement has contributed to. If there are gaps between research activities, we will keep CYP informed on what is happening next.
- At all points in the project we will ensure that CYP understand what will happen to the information they give us and how it will be used.

Risks and safety:

- We will risk assess all activities prior to any involvement by CYP to maintain their safety, including a review of the project safeguarding procedure (please see section 2.3 of this document).
- We will ensure all participants and researchers understand the safeguarding procedures and the limits to confidentiality – if safeguarding action needs to be taken the CYP must be fully informed on this and the associated actions and outcomes.
- We will ensure all participants and researchers understand the safety procedures (e.g. emergency exits, nearest phone, first aider etc.)
- Young people need to fully consent to take part and know how to contact us to withdraw from the project and/or complain should they need to. This includes where to go if further support is required.
- If participants are under 16 they must have a parent / carer consent to take part in activities.
- We will not touch or restrain CYP except in an emergency and will seek their permission to do so wherever possible.
- We will store all information collected according to GDPR principles. CYP should be informed of what information we collect, why and how it will be used and stored.

Benefits:

- CYP involvement in research should benefit them too – either by learning new skills, vouchers, or having fun. We will be clear about how benefits will be rewarded to CYP prior to any engagement.
- Where possible refreshments and snacks will be provided.

Protection and wellbeing of the participants and safeguarding

While there is no risk of physical harm to any participants in this study, and the potential for psychological harm/distress is believed to be extremely low, it is feasible that some participants may have had negative experiences in relation to their own or others' health. It is also possible that the data collection process may cause some participants distress if they find it challenging to express or articulate their views.

To manage this, involvement and engagement methods will be designed to be as accessible and non-threatening as possible for all involved. Overly complicated or difficult-to understand language will be avoided. The use of creative activities will also be used to help support participants' different learning and engagement styles, linguistic competencies and varied confidence levels.

With all interviews, focus groups and workshops, we recognise that we do not know the precise direction that discussions will take. We will remain vigilant to the potential for discussions to distress participants in some way. If a participant becomes distressed in any way, activities will be paused immediately; participants will be asked if they are okay, if they would like a short break, if they require any support and if they would like to continue or withdraw from the activity. With the community organisations with which we are working, we will ensure that we have agreed in advance who will be available to provide support in such instances. If safeguarding issues are disclosed, these will be addressed in line with Action for Children Ethical Guidelines for research which state that:

> *"Researchers need to be clear with participants from the outset that confidentiality may have to be breached if there is a disclosure relating to serious harm, abuse and/or other child protection concerns...*
> *If a participant divulges any information that gives rise to child protection concerns, or where the researcher observes or receives evidence of incidents likely to cause serious harm, the researcher has a duty to take steps to protect the child or other children.*
> *The researcher also has a responsibility to ensure that the person disclosing is aware of the likely consequences, to ensure their wishes are clear and taken into account, to inform them of the steps that the researcher has to take and to offer support for them to tell someone else. They should ensure the individual disclosing is supported and kept informed" (Action for Children Ethical Guidelines for Research[1]).*

[1] *Action for Children Ethical Guidelines for Research. Cited in Sheffield Hallam University (no date). Accessed on 01.05.19 at https://www.google.com/search?q=SAFEGUARDING+CHILDREN+IN+RESEARCH+CONTEXTS&ie=utf-8&oe=utf-8&client=firefox-b-e#)*

Approaching groups of CYP to work with

When approaching CYP groups it is important that we give them as much information as possible in order for them to decide whether they would like to support our research, including what the research involves, how is it relevant for CYP, and the possible benefits. Where possible the following proforma should be used to engage relevant groups:

INFORMATION ON OPPORTUNITY

Contact Details

Name/Position:	
Organisation/Service:	
Phone Number(s):	
Email Address:	

Please outline the methods/data collection activities, and give a brief overview of the project:
e.g. workshops, interviews, PI&E activities, production of guidance

Please provide any specific details, e.g. data collection period, number of interviews/focus groups, time/length of, online/face to face, location of data collection
e.g. data collection period, number of interviews/focus groups, time/length of, online/face to face, location of data collection

Please explain how this opportunity is relevant to young people and will have an impact on their lives, and how you will inform them of the outcome/impact of their involvement:
What are the intended outcomes (e.g. resources, service improvements), will it have immediate impact on CYP lives, will it help provide knowledge for research/practice, will it be fun/enjoyable, and will the findings be presented to the CYP?

Please confirm that you are willing to cover the cost of any expenses incurred and provide details of any other rewards or recognition that will be offered:
We will cover and reimburse any expense costs (e.g., travel) that the young people experience participating in the research, and will cover the cost of refreshments for face-to-face meetings (e.g. drinks and snacks). Each young person who participates will receive a £20 high street voucher as a thank you for their time. The involvement of the young people will be confidentially acknowledged in any publication or work which follows on from this research.

NIHR | School for Public Health Research

This project is funded by the National Institute for Health Research (NIHR) School for Public Health Research (grant reference PD-SPH-2015). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

NIHR | School for Public Health Research

For more information, please contact Eleanor Holding (e.holding@sheffield.ac.uk)
Produced by NIHR SPHR (May 2021)
The information in this report/brochure is correct at the time of printing.