



BANNAR

the barbara ansell national network
for adolescent rheumatology

YOURR Project:

Young People's Opinions Underpinning
Rheumatology Research

***Summary of good practice
when involving young people
in health-related research***

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1. Introduction

The involvement of young people in research is an important ethical imperative (UNCRC 1998) and has been called for by young people themselves (Bate 2012; RCPCH 2016). 'Involvement' can be defined as when researchers collaborate with young people in the planning and management of studies to get patient input at ALL stages of the research process from research priority and question setting right through to dissemination of results.

The BANNAR Young people Underpinning Rheumatology Research YOURR project (Parsons S 2016) was completed in 2016

The original aims were:

- To identify the themes and topics which are important from a young person perspective which will be used to refine and prioritise the future research strategy of the BANNAR
- To explore current and/or prior experience of rheumatology research of young people (including as participants as well as involved in the wider research process) and the expectations of those young people with no such experience
- To determine how and when young people want to be involved in the research process itself from agenda setting through to dissemination
- To develop a youth-led involvement strategy which will ensure their meaningful involvement in future research programmes of the BANNAR. The Your Rheum group was established in autumn 2016 and for further details see <https://yourrheum.org>.

In preparation for the project a scoping exercise was undertaken acknowledging that many organisations involve young people successfully to get their input on decisions throughout the research process. We identified the main UK leaders in this field and approached them to find out more about their experience and ask for advice and resources they could share. This report summarises our updated key findings of that preparatory work. We will use this learning in the YOURR project as it moves forward, but we also hope it can be a useful to others with an interest in this area.

Involvement encompasses a range of activities where patients/publics work alongside researchers, such as helping to identify new ideas for research, contributing to the design of studies and offering feedback on patient information sheets. This type of activity is also sometimes described as 'participation'. These activities are distinct from people being recruited to research studies and taking part as a participant.

2. Acknowledgements

We would like to express our sincere thanks to all of those who kindly shared their experiences with us.

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3. Key considerations when involving young people in medical research

There are many documents that describe good practice when involving adults in medical research and many of these principles apply with young people too, such as providing clear information for individuals to understand what is expected of them from the start. We have summarised below the main, general considerations we've identified when involving young people with research successfully:

3.1. General Considerations when involving young people in your research

Planning and supporting involvement

- It takes considerable resource to set up and establish a young people's group, so bear this in mind before starting to set one up.
- Be mindful of young people's time constraints (i.e. school, college, family, social life) and arrange meetings accordingly (i.e. not during exam periods; afternoon rather than morning meetings etc.). Ideally, ask the young people involved what's best for them.
- It's important to try to attract a good mix of young people across the social classes including both genders, young people from ethnic minorities, young people with disabilities and marginalised young people such as those in care.
- Most groups recruit continuously, which mitigates for young people leaving. Be mindful of young people approaching the upper age limit and support their "transition" out of the group.
- It's always good to offer further opportunities, if possible, when young people get older - e.g. adult advisory groups, volunteering opportunities etc.
- Consider how to maximise accessibility, safety and ethical standards.

Approach to involvement

- Be flexible in your approach - often it is more productive to have a mix of short and long term aspirations to maintain engagement.
- Listen to what the young people really want - do not assume you know. Clarification of their views if required should be done in a non-judgmental way. Professionals should consider the words they use and avoid the use of jargon.
- Show young people that senior researchers are really interested in hearing their views and will take them seriously.
- It's important to reward and incentivise where appropriate (e.g. social events, certificates, awards) and provide necessary information for the young people to include in their career portfolios etc.
- Find a facilitator who is welcoming, and an excellent communicator with young people. Make this person a long-term point of contact for the young people so they can develop a positive relationship over time.
- When a group first meets think about how you can help the participants to introduce themselves and build trust and openness between members of the group e.g. ice-breakers etc.

Managing expectations

- Ensure that the young people understand that research is a lengthy process and that there are often no immediate tangible benefits. Also not all ideas or projects will succeed or be feasible or practical.

3.2. Guidance on involvement of young people

Develop a plan for involving young people which considers:

- What the existing evidence is for, what do young people think about the issue being studied
- Why young people are being involved
- What will be their role and remit in relation to the research
- How will young people be involved, i.e. what method of involvement would best suit the aims, objectives, resources and participants of the project. It is preferable to use a variety of methods and involve young people in the choice of methods to be used
- How can you ensure that their involvement is not tokenistic – e.g. clearly defining roles, establishing what will support young people's involvement and what will support those doing the involving
- Ensure the proposed involvement fulfils the criteria for one of the 5 degrees of participation:
 - Assigned but informed
 - Consulted and informed
 - Adult-initiated, shared decision-making with young people
 - Youth-initiated, shared decision-making with adults
 - Youth initiated and directed

And is NOT non-participation (ie tokenism, decoration, manipulation. (see RCPCH Not Just a Phase (2010)

- Develop a clearly documented involvement plan which also highlights how involvement of young people is likely to add value

Points to consider when developing your involvement plan:

The environment

- The ethos, culture and environment in which young people participate should be safe, age and developmentally appropriate.

Recruitment

- Recruitment strategies should be designed to reach young people across the social classes including both genders and young people from marginalized groups e.g. in care, black and minority ethnic young people and those with disabilities.
- If the focus of the project is adolescent (10-19), ideally involve adolescents rather than a young adult (in their twenties) recalling their adolescence.

Facilitator

- Identify a staff member with the necessary skills to be responsible for facilitating the involvement. They should be responsible for the briefing of both young people and key professionals (e.g. chair of a steering group) prior to the activity and be available for de-briefing of the young people after.

- Should ensure there is good written publicity about the group so that young people feel properly informed before they agree to take part.

Chair (adult predominant meetings e.g. steering or advisory groups involving young people as active participants)

- Ensures the young people are welcomed and introduced to the other participants including their name, what they do and why they are there.
- In predominantly adult meetings, ensure the facilitator sits with the young people to explain anything during the course of the meeting.
- Is attentive and actively involves the young people, acknowledging some may be less confident, so that they are given time to have input on discussions.
- Directs questions to the young people, when appropriate, in order to ascertain their views and ideas on the topic.
- Ensure questions that are directed at young people are clear and precise.
- Ensure participants avoid jargon and explains any medical terms or abbreviations during the meeting.
- Ensure the young people are clear about the decisions that have been made at the end of the meeting.

Meetings organisation and delivery

- The facilitator should ensure the young people understand the purpose of the meeting, their particular remit in the meeting, who else will be there and what will happen at the meeting(s), including how differing opinions will be heard.
- The facilitator should discuss with the young people beforehand how they would like to participate in the meeting(s) and ensure that they have the necessary information to enable them to be prepared and think of issues beforehand.

Manner of Involvement of young people in an activity

- Ideally the young people should have a choice over how they are involved including timing, pacing etc.
- Ensure the process is accessible to the young people. If it isn't, can it be made so. E.g. could a separate exercise be run with young people, the results of which can then be presented to the adult-led group, ideally by representatives of the youth-led group.
- Take care with long meetings and ensure adequate breaks, accommodate their long term conditions and acknowledge the attention spans of young people. Ensure young people have enough time to formulate and/or express their opinion.

Post-involvement considerations

- Ensure the young people have an opportunity to talk about how they thought the activity went. This should be fed back to the organisers.
- Ensure that young people are clear as to what happens next and who will do what.
- Ensure feedback is provided on both their involvement as well as the research outputs/minutes.
- Ensure expenses are covered and evidence of their involvement (certificate for their CV) provided.

Accreditation of involvement for young people

- It is important to consider how to remunerate and reward involvement of young people and there is good guidance now available for this.
<http://www.invo.org.uk/resource-centre/payment/>

<http://www.participationworks.org.uk/resources/how-to-remunerate-and-reward-children-and-young-peoples-involvement>

- One way is to seek accreditation of their involvement which can then go towards their vocational development. Two examples of these are listed below.
 - ASDAN
<http://www.asdan.org.uk/home>
 - Youth Achievement Awards
<http://www.ukyouth.org/accredited-learning/youth-achievement-awards>

4. Models of Good practice



4.1. Children's Speciality theme in the NIHR Clinical Research Network (CRN)

<http://generationr.org.uk>
<https://www.nihr.ac.uk/nihr-in-your-area/children/>

The **Children's Speciality Theme in the NIHR Clinical Research Network** is one of 30 Specialities, which brings together communities of clinical practice to provide national networks of research expertise. The Children's Speciality Theme supports therapeutic clinical trials and pharmacokinetic, pharmacodynamic, pharmacovigilance and other high quality studies in all therapeutic areas except children's oncology

The Children's Speciality Theme is supported by a National Young Person's Advisory Group (YPAG) set up in 2006. The group now called **GenerationR** (R for Research) consists of five groups across the country (Liverpool, Birmingham, Bristol, Nottingham and London). Groups are funded by the NIHR and/or NHS Organisations through various sources. The groups support the design and delivery of paediatric research in the UK.

With specific reference to paediatric rheumatology and musculoskeletal disorders, there has been very close collaboration since 2007 between with the NIHR CRN and Arthritis Research UK through the work of the NIHR CRN: Children / Arthritis Research UK Paediatric Rheumatology Clinical Studies Group. This has had a very strong patient and public involvement focus throughout, including up to four parent/patient representatives on the main CSG, and other representatives involved in all of the CSG's activities. Since 2014, this has been extended significantly with the advent of the UK's first and only Experimental Arthritis Treatment Centre for Children (EATC4Children), supported by Arthritis Research UK and in close collaboration with the NIHR Alder Hey Clinical Research Facility for experimental medicine. The EATC4Children leads a comprehensive translational programme to improve the health and well-being of children with paediatric rheumatic disorders. This platform of internationally competitive expertise is fully integrated with existing national collaborative strengths and NIHR infrastructure, with meaningful patient and public involvement and engagement (PPIE) at its very core. It seeks to develop and deliver experimental medicine and early phase clinical trials in paediatric musculoskeletal disorders relevant to children and young people with paediatric rheumatic disorders. The EATC4children is fully supported by the GenerationR Liverpool YPAG; Rheumatology focused support groups, and Young Patient Research Ambassadors.

The GenerationR Liverpool YPAG meets every six weeks in the Institute in the Park at Alder Hey Children's Hospital. The group continues to support members of the EATC4Children by providing a forum for advice to researchers working on paediatric research. It provides a one-stop shop support service to researchers working on studies that fit the EATC4Children and wider research remit. All of the EATC4Children's PPIE activities continue to be promoted via the GenerationR website <http://generationr.org.uk/liverpool/> and was developed by young people to promote awareness raising of testing treatments to a young audience, which includes working with schools, patients, and members of the public.

Key advice provided by Jenny Preston
Patient and Public Involvement Manager:
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Recruitment

- Recruitment is an on-going process and membership to the YPAG is through a staged approach. Young people are asked to apply for a place in the group and sign a young person's agreement, which sets out the role and expectations of all members. The young person is then invited to attend a meeting so they can decide if this is a group they want to be part of.

Planning and organisation

- The Liverpool YPAG currently has 16 members (aged 11-20) from the Merseyside region. Approximately 14 members attend each meeting.
- Running meetings from 11-3pm on a Saturday has worked well and allows lots to be achieved in that timeframe.
- Texting young people to remind them of meetings works better than any other form of communication (i.e. emails or letters).
- Members are offered £20 LovetoShop or Amazon vouchers for attending meetings.
- Travel expenses are covered

Training and support for involvement (For young people and researchers)

- Young people need training about research methods and systems and this can be built into sessions with researchers.
- It's important to brief researchers and work with them to help them explain their study and exactly what they want from the young people and invite them to the meeting so they can meet directly.
- Access needs are considered and accommodated.
- A thank you letter is given to members from researchers presenting to the group acknowledging their time and input as well as for their records of achievement portfolio.

Involvement process /facilitating involvement

- Some members of the group have remained active since the YPAG was established in 2006.
- Important to use ice-breakers and ethical debates to help stimulate the group.
- It's very important that young people see things happen as a consequence of their input and get feedback from researchers.
- It is important to offer a wide variety of opportunities for young people to speak at conferences, events and meetings. Group facilitators support them in this role.



4.2. Centre for the Development and Evaluation of Complex Interventions for Public Health Improvement (DECIPHER)

<http://decipher.uk.net/>

DECIPHER is a UKCRC Public Health Research Centre of Excellence. It brings together leading experts from a range of disciplines to tackle public health issues, with a particular focus on developing and evaluating multi-level interventions that will have an impact on the health and wellbeing of children and young people.

A core principle of DECIPHER's work is that children, young people, their carers and parents should be actively involved. The key objectives are to:

- involve the public in the strategic development of DECIPHER
- involve the public in the research process within individual projects
- increase awareness and opportunities for public involvement in DECIPHER research
- and develop the capacity within DECIPHER to involve the public in its work

Public involvement is undertaken in the Centre through employing a full time 'Involving Young People Research Officer' who supports and organises two groups: a young people's advisory group (ALPHA: Advice Leading to Public Health Advancement) and a Public Involvement Steering Group made up of academics and practitioners with a sound understanding of public involvement. (https://www.youtube.com/watch?v=N2jec2k_vkw)

Key advice provided by Peter Gee

Public Involvement Officer:

geep@cardiff.ac.uk - 02920 687217

Recruitment

- The young people are recruited through a stepped approach. Firstly visiting young people in places they are comfortable (e.g. youth clubs and schools) and giving them clear information on what the groups role is. The second step is to invite young people to come into the University, with support from a trusted adult if they wish (e.g. a youth worker), for a trial meeting so they can decide if this is a group they want to be part of.

Planning and organisation

- The ALPHA group has 27 members (aged 14-23) and they are from South Wales. Generally about 14 members attend each meeting. Meetings are held at Cardiff University.
- They run monthly meetings, but no meeting in May due to exams or August as the group instead attend a residential weekend away. The meetings are held on Saturdays between 12-3pm. The meetings don't start until 12 as some young people travel into Cardiff from other parts of South Wales.
- They use Facebook, email and texting to advise young people what will be discussed at the next meeting, and remind them of upcoming events and meetings.
- Attendees are offered £15 in Lovetoshop vouchers per 3 hour meeting. Some young people are on benefits and (at the time of consultation) £15/month does not exceed permitted DWP threshold.

- Travel expenses covered.

Training and support for involvement

- Training sessions are run with young people on research and public health.
- After young people review a project, researchers are given three important issues to take away with them. This helps to focus the young people, and the feedback from the researchers.

Involvement process / facilitating involvement

- The Centre held a welcome meeting at the start and young people could bring along youth service workers to support them. Getting to know activities used and young people had an opportunity to find out what types of projects ALPHA have/will work on.
- The group have written a constitution with 'ground rules'.
- Members decided they did not want to take on specific roles.
- Group activities are made as practical and visual as possible. Lots of youth work based exercises are used including spider diagrams and a hot air balloon activity (where a research project is framed as a hot air balloon).
- Sessions are also audio recorded so researchers can listen back to session and ensure all voices heard.

4.3. Royal College of Paediatrics and Child Health – The Children and Young People’s Engagement Team

www.rcpch.ac.uk/and_us

The **Royal College of Paediatrics and Child Health** is a UK wide charity whose mission is to transform child health through knowledge, innovation and expertise. We are responsible for training and examining paediatricians in the UK, as well as improving child health through research, standards, quality improvement and policy.

The **Children and Young People’s Engagement Team** at the College works to ensure that the voice of children, young people and families is making a difference in child health and healthcare for young patients. Through delivering the **&Us®** network for children, young people, parents and carers; and the **Engagement Collaborative** for professionals, we actively seek and share the views of children, young people and families in order to influence and shape policy and practice.

The **Children and Young People’s Engagement Team** aims to:

- Ensure that children’s rights are understood, protected and promoted
- Create opportunities for children and young people (aged 10 – 25) and their families to inform and influence all aspects of College work
- Collaborate with networks of children, young people, families and professionals across the UK to improve child health experiences and services

The voice of children and young people extends to other areas of College work including education and training of paediatricians, research and policy, business development, health promotions, media, publications and more.

Our work is delivered through four engagement elements of ; *Inform, Consult, Involve and Represent* . Strategic voice of children and young people is supported through partnership work with children, young people, families, health care professionals, formal and informal education providers, social care, local and central government and the voluntary and community sectors.

We also try where possible to ensure we are working with a range of children and young from different ages, backgrounds, experiences and locations for a diverse set of voices.

The strategic voice programme includes:

&Us® network - children, young people and families

- Social media platforms, monthly opportunities newsletter
- **&Us®** projects: developing and delivering long term projects to improve health services
- **&Us®** challenges: one day challenges to improve voice in health

- **&Us**[®] roadshows: to capture voice through consultation workshops across the UK
- **&Us**[®] academy: our offer to CYPF with training, mentoring, support and a range of nationally recognised awards, accreditations and qualifications recognising their voluntary activity and skill development

Engagement Collaborative - child health / health care engagement leads

- Share good practice through a monthly bulletin
- Collaborative consultation responses
- Information, advice and guidance on creating strategic voice programmes
- Access to a network of local champions and experts in engagement

Published Guidance:

Infants, Children and Young People's Child Health Research Charter is a set of guiding principles developed by young people themselves to support professionals working with or involving children and young people in research.

<http://www.rcpch.ac.uk/cyp-research-charter>

Engagement and Involvement 101 for health settings and commissioners - <https://www.rcpch.ac.uk/andus-participation>

- Legislation briefing
- Engagement activities booklets – Recipes for Engagement
- Case study examples
- Top tips for healthcare professionals and commissioning guidance
- Voice and Choice action pack to start engagement locally
- Video clips on messages from CYP and Rights at our YouTube Channel ... and more!

Recruitment

- Volunteers are recruited into the **&Us**[®] network through a sign up process online or at taster sessions
- Promotional material is also used
- The use of social media has become an important tool to raise awareness about the network, its activities and projects as well as to support other likeminded initiatives.

Planning and organisation

- A network of volunteers requires a range of clear and concise participation policies/guidance which are shared and implemented e.g. creative engagement approaches, volunteer handbook, social media guidelines, risk assessments, travel costs covered in advance where possible or reimbursed
- Having a broad age group (10-25) will also specifically require different policies and processes for those pre and post 18 years of age. (e.g. parent/carer consent). Consultations are aimed at ages 2 – 25 years
- The network has a UK wide remit
- The use of technology such as GoToMeetings is becoming increasingly necessary to bring together network members from across the country
- It is important to remember that children, young people and families have busy lives and require reasonable notice like anyone else. A flexible approach is best, going to them wherever possible e.g. through clinic chats and it is important to be prepared to make changes, which may impact on project timelines.

Training and support for involvement

- A briefing pack and/or background reading (where relevant) is provided for each activity a child, young person or family members takes part in which include details of the event, what their role and remit is as well as any logistics and access to support
- Bespoke training and/or coaching can be offered to ensure the child, young person or family member is comfortable and adequately prepared
- Access needs are considered and accommodated
- A debrief following their participation is offered which can be simply a short conversation, email about the activity or a summary report
- A thank you letter/certificate is given to participants acknowledging their time and commitment as well as for their records of achievement portfolio.

Involvement process / facilitating involvement

- Opportunities/activities for engagement are shared with volunteers via a monthly newsletter Role profiles are created for activities and a selection criteria set, which provides further clarity, expectations to ensures fairness
- Having a flexible engagement project which meets the needs of the children and young people is vital, with different opportunities, going to their settings and being flexible on styles of engagement to meet their needs
- Opportunities/activities are risk assessed to make sure they are age appropriate and safe for CYP
- Opportunities/activities through a Roadshow or Clinic Chat model go to children, young people or family forums through existing groups such as universal settings (schools / youth clubs), targeted settings (patient forums, condition forums) or specialist (inpatient units, treatment centres) to increase engagement by going to them and to ensure the range of voices are heard
- &Us Challenges provide taster projects within 5 hours where children, young people and / or families learn about a topic such as The State of Child Health (RCPCH 2017), review, prioritise and then action plan, presenting their findings to key decision makers
- It's important to feedback to children and young people with how their involvement has impacted on the work they did and share any outcomes.

Key advice provided by

Hana Najsrova - Children and Young People's Participation and Advocacy Coordinator

Emma Sparrow - Children and Young People's Engagement Manager

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4.4. The Association for Young People's Health (AYPH)

<http://www.youngpeopleshealth.org.uk/>

<http://www.youngpeopleshealth.org.uk/our-work/young-peoples-participation>

AYPH is a progressive charity and membership forum, creating a focus for everyone working in the field of young people's health across the UK. With their members, they aim to promote and support the health and well-being of young people by:

- Encouraging and facilitating more effective communication between practitioners
- Working to raise the profile and understanding of young people's health needs
- Improving access to information, resources, innovation and best practice
- Promoting evidence-based practice by making research findings more accessible and supporting new studies into young people's health

Young people have a right to good health and high quality accessible healthcare. AYPH brings together professionals and organisations working to improve young people's health and well-being. They are also currently working to develop a youth-led research agenda for health.

Key advice provided by Emma Rigby, CEO of AYPH

Recruitment

- No details provided.

Planning and organisation for a recent AYPH project – “Be Healthy”

<http://www.ayph-behealthy.org.uk/>

- The young people advising the ‘Be Healthy’ project met seven times over 2 years. There were 20 members (aged 11-18) and they met in youth services premises. 8-10 people attended each workshop. They were from the Bedfordshire region.
- Travel costs were covered for attendees but nothing more.
- Project had a discrete end. A challenge was planning for 'what next?'
- They decided to close their Facebook page. Important to have clear guidelines on what and how to share information.

Training and support for involvement

- Peer support provided through membership was a huge draw for attendance.
- To raise awareness of their work, they created a website (with very striking graphics), booklet, confidentiality comic, animated film and postcards.

Involvement process / facilitating involvement

- Need to consider gender balance, ethnic balance, health challenges. Be clear that you are not representative of the entire disease group and recognise that not all young people will want to be part of the group. Are there alternative means of engagement for these? ‘Be Healthy’ recruitment was initially a challenge, but once engaged, successfully retained people over a two year period.
- Ground rules were set at the outset. Clear, achievable expectations of group set out. Main success factor is to have a good participation worker. Ensure it is truly participative process and that young people have a positive experience.

- Young people grow up, so need to be flexible - reflect and evolve. Do all you can to ensure young people's expectations are the same as staff.
- A planned outcome was ASDAN accredited award in PSHE.

4.5. Birmingham Children's Hospital

Birmingham Children's hospital provides the widest range of children's health services for young patients from Birmingham, the West Midlands and beyond, with over 257,000 patient visits every year.

This hospital has a Young Persons' Advisory Group (YPAG) and its main aim is "getting involved and making a difference" at Birmingham Children's Hospital. The group was launched in January 2010 and has been meeting regularly since. YPAG keeps in regular contact with more than 60 young people (aged 11-19) via email and text. This group discuss a wide range of health issues, not just research.

Further info: [BCH Young Person Advisory Group \(YPAG\)](#)

Key advice provided by Dave Baker Senior Youth Worker
david.baker@bch.nhs.uk - 07747 027436

Recruitment

- Need to constantly recruit. Criteria for entry deliberately loose for maximal diversity. Looked after young people are under-represented. Need to acknowledge conflicting pressures as well as differences in organisational skills between young people and adults eg more reminders of events, over-invite to meetings, as some won't make it.
- Group developed logo and mascot (and helped with content for website and leaflet) which helps to raise awareness and find new members.

Planning and organisation

- There are four main meetings a year, usually on a Saturday, 12-2pm held at the hospital. Monthly sub-meetings, usually on a weekday, 5-7pm. Other meetings in between for special events and outings.
- Email and texting used to communicate with members, but rarely phone calls. They text members to remind them about meetings. Facebook used by young people if they wish - but not used in official capacity by group. Ground rules (IG, Caldicott) made.
- Thank you rewards such as pizza and concerts are important. Travel costs are not reimbursed and no other token/honorarium offered. Accreditation offered via ASDAN, BYS, "V" involved. Support with college/job references and certificates of attendance well received by young people.
- Socials and residential successful but require significant organisation including safeguarding issues, risk assessment etc and funding.

Training and support for involvement

- Important to get senior buy-in and feedback when young people have contributed.

Involvement process / facilitating involvement

Initially meetings were chaired by adult facilitator, but once established (2 years), youth members became chair and VC. Chair, VC and admin support roles are paid for their input.

- Delicate balance between spoon-feeding and empowerment.
- Balance quick wins with longer projects to retain interest.
- Important role for advocates with young people with certain conditions eg autism, Asperger and ADHD.

4.6. Centre for Children and Young People's Participation (UCLAN)

http://www.uclan.ac.uk/research/explore/groups/centre_young_people_participation.php

Based at **The University of Central Lancashire's School of Social Work**, and founded in 2008 by Professors Nigel Thomas and Andy Bilson, the **Centre for Children and Young People's Participation** is the only research centre devoted to this theme, and has an international reputation for research and knowledge exchange. It has conducted research for a wide range of bodies including governments, NGOs and international organisations, and has associates all over the world.

The Centre is a member of Eurochild and a founding member of the International Childhood and Youth Research Network. In 2012 The Centre hosted the second international conference of the Network, which was ground-breaking in the way that it included children and young people at every stage in the planning and running of the event, and in promoting it afterwards. Our regular seminars are attended by a wide range of researchers, students, practitioners and policy-makers. Children and young people are involved in all aspects of The Centre and its functioning, and have been actively involved in and contributed to recent research projects.

In 2013 The Centre conducted research for the Children's Commissioner for England to help understand the impact of poverty on disabled children's rights, which was groundbreaking in that the research was co-led by young people with disabilities who were then able, in partnership with the Commissioner's office, to use the research to influence policy and have formed themselves into a permanent research group supported by The Centre. The Centre also specialises in supporting children and young people to propose, plan and carry out their own research, as well as being partners on adult research projects.

Key advice provided by Dan Moxon

Centre Co-Director Cath Larkins recently worked with young researchers from the Centre to review several youth-led pieces of research and identify "Essential Ingredients in Child and Young Person Led Research" (Larkins & Young Researchers, 2014). Young people from the group recommended:

- Think about research as made up of lots of stages
- Think about young people having different influences in different stages of the research, according to their own choice and interests
- Give individual children and young people the support they need so they can engage in different stages of research in ways they want to
- Adapt methods and provide different activities for different young people within the group
- Build trust
- Value differences in opinions but work towards agreements
- Adult should back off
- Make it fun

The full text can be found at:

Larkin, C. & Young Researchers 2014, "Essential Ingredients in Child and Young Person Led Research" in *Participation, Citizenship and Intergenerational Relationship in Children and Young People's lives: Children and Adults in Conversation*, eds. J. Westwood, C. Larkins, D. Moxon, Y. Perry & N. Thomas, pp. 109-119.



4.7. Transition – the United Progression (UP) Young People’s Involvement Group

Northumbria Healthcare NHS Foundation Trust and Newcastle University
<http://research.ncl.ac.uk/transition/>

UP is a working group of young people with health needs, or personal experience of young people’s health needs, who work with the Project Management Board of the 5 year NIHR Transition Research Programme examining how health services can contribute most effectively to facilitating successful transition of young people with complex health needs from childhood to adulthood. UP was established to advise the full programme in addition to developing for their own youth led work stream. To date they have been involved in developing the research questions, research design and methods, fieldwork as peer interviewers and are due to be involved in research analysis, product development and dissemination. Funding is from the NIHR programme grant and includes: Travel to meetings; hot food and beverages at meetings; 3 Peer support workers (voluntary role, not funded), defined sessional time from the following support staff: administrator, participation worker, research assistant (with a PPI role) and co-applicant work stream lead (Clinical Psychologist); funding available for attendance at dissemination events later in the programme; annual accreditation to allow the members to gain their Youth Achievement Awards.

Key Advice provided by: Dr Gail Dovey-Pearce (Consultant Clinical Psychologist) Research Co-applicant and the Transition programme Involvement Lead
gail.dovey-pearce@nhct.nhs.uk - 0191 293 4193

Recruitment

- The peer support workers PSW were existing members of the host Trust’s local youth advisory group and they nominated themselves and were interviewed for the PSW role. The initial tasks of the PSW were to support the recruitment to the programme’s young people’s advisory group, to help induct young people to the group and to participate as interviewers, alongside the adult researchers, in the recruitment of the programme’s research associates.
- The recruitment strategy focussed on approaching young people with experience of the exemplar conditions (autism, cerebral palsy, diabetes) but who were not eligible for participation in the longitudinal study.
- Initial meetings took place with the young person and other people of their choice (e.g. teacher; family member) to ascertain the best way to engage and support the involvement of each individual.

Planning and organisation

- Age-range 16-24, mean age 20. In total, twenty-six young people have attended the group since its inception. Of these, there are 14 core members that continue to attend regularly, two years into the programme (Males 43%, Females 57%; direct experience of one or more of exemplar conditions 79%. The twelve other members have either decided to leave or remain as occasional members / receiving email updates.
- The group called itself United Progression (UP), designing their logo and group information. They meet monthly, on a Friday evening. They receive an email reminder of the content of the previous meeting and a proposed agenda.

- Young people are funded to get their Youth Achievement Awards.
<http://www.ukyouth.org/training-and-accreditation.html>

Training and support for involvement

Young people are telling us that they are getting so much more than research skills and CV content from taking part. They are telling us about the personal importance of being part of the group: communication skills development; confidence; self-awareness...etc.

Involvement process / facilitating involvement

- The group have a hot meal at the venue together, with time to socialise, followed by an ice-breaker and a reminder of the meeting agenda. The meeting is then task-focussed and goal-oriented. Methods used included: small group exercises; accessing 'training' resources and external speakers; revisiting concepts in different ways; quizzes and brainstorming to know how group are understanding concepts, before generating their ideas.
- The Peer Support Workers remain as part of the group and now support the facilitation of these group exercises at the meeting and taking part in the planning and preparation with the staff team.
- Evaluation methods included staff reflective diaries, post meeting de-brief, feedback from young people; parents and support staff on methods being used and impact upon young people. A satellite research project formally evaluating the initiative is planned.
- Important to acknowledge involvement is never static but evolves in cycles.
- Need to build up slowly at the pace of the young people participating allowing time for concept development; skills development; confidence building. Ideally build in a period of time for group formation and skills development at start of the project.
- On-going communication between all stakeholders is key to developing clear PPI goals and tasks, as the research progresses, so that expectations are realistic and timelines achievable.
- The Co-Applicant/Involvement Lead attends all of the UP meetings and is considered by the young people as part of the group team. This enables swift and clear communication between the young people and the project managers and vice versa.

5. Key web-based resources

5.1. Global Research in Paediatrics

- Global Research in Paediatrics has an online step-by-step guide to starting up a Young Person's Advisory Group.
<http://ypag.grip-network.org/starting-up-a-ypag/>

5.2. INVOLVE

- INVOLVE is funded by the [National Institute for Health Research](#) (NIHR) to support public involvement in NHS, public health and social care research.
<http://www.invo.org.uk/>
<http://www.invo.org.uk/find-out-more/involving-children-and-young-people/>

5.3. National Children's Bureau

- The National Children's Bureau (NCB) is a leading children's charity that for 50 years has been improving the lives of children and young people, especially the most vulnerable.
- They have a youth membership group, [Young NCB](#), who speak out on the issues that affect children and young people in society. Young NCB members choose priority subjects that they think are the big issues for children and young people and find ways of tackling these.
- The NCB involve young people in their research because they believe it improves the quality of the research and makes it more relevant and more persuasive for policymakers and practitioners. They train young people to consult and collaborate on research projects. An example <http://www.ncb.org.uk/>
- **PEAR** - which stands for Public health, Education, Awareness, Research - was an NCB Research Centre project supporting young people's involvement in public health research. The project ran from 2008-2010, supported by the Wellcome Trust. The PEAR group was made up of 20 young people, aged 13-18, from London and Leeds. A key output of this work was guidance for researchers:
 - ***Young People in Research: How to involve us Guidance for researchers from the PEAR young people's public health group***
<http://www.participationworks.org.uk/resources/guidelines-for-research-with-children-and-young-people/>
 - An example of NCB work in this area is **The VIPER project**, consists of 16 young disabled people, aged 12 to 22, from across England. Resources developed as part of this project are available on the website.
<http://councilfordisabledchildren.org.uk/our-work/participation/policy/research-young-peoples-participation-local-decisions-viper>

5.4. National Youth Agency

- The National Youth Agency believes that now more than ever young people need youth workers. Youth workers dedicate their time and expertise to helping young people in their personal and social development. The National Youth Agency supports youth workers.
<http://www.nya.org.uk/>

- The National Youth Agency's Young Researcher Network (YRN) has launched toolkits to help young people undertake youth-led research and promote their findings:
http://www.nya.org.uk/resource_category/young-researchers-network/

5.5. NHS England and the British Youth Council

- Bitesize guide to setting up a Youth Forum in Health Services across England.
<https://www.england.nhs.uk/?s=youth+forum+guide>

5.6. Nuffield Council on Bioethics

- Children and clinical research: ethical issues (2015).
<http://nuffieldbioethics.org/project/children-research/>

5.7. Participation Works

- Participation Works is a consortium of seven national children and young people's agencies that enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives.
<http://www.participationworks.org.uk/>
- They offer: [training and consultancy](#); a national network of participation workers (the [Participation Works Network for England](#)); and an online Gateway that offers a wide selection of information, the [latest news](#) and supporting [resources](#) on participation.

5.8. Understanding Health Research

- This website offers a free, interactive service designed to help people better understand complex health research and "go beyond the headlines". Designed to be useful for a range of people including patients, carers, students, policymakers, health professionals, researchers and those working in the third sector, the site guides users through the process of understanding health research.
<http://www.understandinghealthresearch.org/>

5.9. Youth Health Talk Online

- This website enables patients to share their experiences online. 'Youthhealthtalk.org' and 'Healthtalkonline.org' come from a unique partnership between The DIPEX charity and [The Health Experiences Research Group](#) (HERG) at Oxford University's Department of Primary Care.
<http://healthtalkonline.org/young-peoples-experiences>
- There's a section about young People's experience with clinical trials and research:
<http://www.healthtalk.org/young-peoples-experiences/clinical-trials-medical-research/topics>
- There's a section about young people's experience living with arthritis:
<http://www.healthtalk.org/young-peoples-experiences/arthritis/topics>
Over 40 young people and 10 parents have shared their personal stories on film. They talk about issues such as diagnosis, treatments, school and social life.

6. Additional resources

6.1. Guidance

- **NHS England**
Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England. (April 2017).
<https://www.england.nhs.uk/publication/?filter-keyword=patient+and+public+participation+in+commissioning+health+and+care%3A+statutory+guidance+for+CCGs+and+NHS+England&filter-category=&filter-publication=&filter-date-from=&filter-date-to=>
- **NHS Youth Forum**
Top tips to involving young people in patient participation groups (copy & paste links into web browser)
<http://www.byc.org.uk/wp-content/uploads/2017/07/NHS-Youth-Forum-Brochure-for-PPGs.pdf>

Top tips to involving young people in health care planning
<http://www.byc.org.uk/wp-content/uploads/2016/09/NHS-Youth-Forum-Tip-Brochure-FINAL.pdf>

Poster to assure young people that their feedback will be taken seriously
<https://www.england.nhs.uk/wp-content/uploads/2015/08/yth-rights-in-hlthcr-feedback.jpg>
- **Public Involvement Impact Assessment Framework (PiiAF)**
PiiAF has been produced to help researchers assess the impacts of involving members of the public in their research in diverse fields from health care to local history.
<http://piiaf.org.uk>
- **Research Councils UK**
Research Councils UK have provided a guide for researchers and teachers on how to engage young people in research.
<http://www.rcuk.ac.uk/publications/researchers/engaging/>
- **Royal College of Paediatrics and Child Health**
Children and Young People's Child Health Research Charter is a set of guiding principles developed by young people themselves to support professionals working with or involving children and young people in research.
<http://www.rcpch.ac.uk/cyp-research-charter>
- **The Children and Young People's Commissioner Scotland**
Developed 7 Golden Rules for Participation.
<https://www.cypcs.org.uk/education/golden-rules>

6.2. Toolkits

- **Children’s Commissioners for England**
A range of publications on child participation.
<http://www.childrenscommissioner.gov.uk/learn-more/childparticipation/publications>
- **Children’s Commissioner for Wales**
Resources on helping children and young people understand their rights.
<http://www.childcomwales.org.uk/about-us/childrens-rights/>
- **Disability Matters**
A range of free e-learning resources for professionals to support understanding disability and communication with disabled children and young people.
www.disabilitymatters.org.uk
- **NIHR CRN: Children Clinical Studies Groups (CSGs)**
This toolkit has been developed by consumer members of National Institute for Health Research (NIHR) Clinical Research Network (CRN): Children Clinical Studies Groups (CSGs), to provide practical guidance to other consumer members involved in the research processes of CSGs. The contents of this toolkit are suggestions based on consumers’ experiences working within the NIHR CRN: Children network.
https://www.researchgate.net/publication/312232364_Clinical_studies_groups_a_toolkit_for_patient_parent_and_carer_representatives
- **PEER project**
Training manual for professionals working with young people. The Magic 6, participatory action and learning experiences with Roma Youth.
<http://www.peeryouth.eu/deliverables>
- **Public engagement: a practical guide**
A resource from NIHR and Sense about Science exploring a 5-step guide to involving the public in communicating your research.
<http://senseaboutscience.org>
- **Qualitas Consortium**
The 15 Steps Challenge for children and young people’s inpatient services. The 15 step toolkit to support involvement of CYP and their families in improving quality of inpatient care.
<https://www.qualitasconsortium.com/index.cfm/programs-services/15-steps>
- **The Children and Young People’s Commissioner Scotland**
Developed 7 Golden Rules for Participation.
<https://www.cypcs.org.uk/education/golden-rules>
- **The Commissioner for Children and Young People Order in Northern Ireland**
An active Youth Panel supporting the work of the commissioner.
<http://www.niccy.org/professionals-practitioners-policymakers/participation/what-we-do/>
- **The Council for Disabled Children**

Provides resources and materials to support involving children and young people with disabilities.

www.councilfordisabledchildren.org.uk

- **Together**

A Guide to Engagement with Families – Participation in Practice by Action for Sick Children Scotland (2017). This toolkit is aimed at a range of professionals who wish to develop their knowledge and skills in this area and in particular gain practical ideas of how to gather their stakeholders' views as part of their every-day practice.

<http://www.togetherscotland.org.uk>

6.3. Information and reports

- **Association of Medical Research Charities**

Report, *Our Vision for Research in the NHS* (2013).

<http://www.amrc.org.uk/publications/our-vision-research-nhs>

- **Coram Voice**

Enables and equips children and young people to hold to account the services that are responsible for their care. We uphold the rights of children and young people to actively participate in shaping their own lives.

<http://www.coramvoice.org.uk/>

- **Frontiers for Young Minds**

Frontiers for Young Minds is a US based non-profit scientific journal for which young people serve not only as the target audience, but also as critical participants in the review of manuscripts written by expert researchers. They connect 8-15 year olds directly with leading scientists to provide feedback on articles about cutting-edge discoveries. The end result is a journal of freely available scientific articles that are written by leading scientists and shaped for younger audiences by the input of their own peers.

<http://kids.frontiersin.org/about/>

- **HQIP case study: involving children and young people for quality improvement**

This is a case study from the NHS Youth Forum, who work in partnership with NHS England, Public Health England and the Department of Health to involve children and young people in healthcare quality improvement. It demonstrates the importance of using the views of young people, the results of partnership with young people, and the use of social media to reach young people.

<http://www.hqip.org.uk/resources/case-study-involving-young-people-quality-improvement>

- **National Institute for Health Research**

Report, *Going the Extra Mile: Improving the nation's health and wellbeing through public involvement in research* (2015).

<https://www.nihr.ac.uk/news/going-the-extra-mile-a-strategic-review-of-public-involvement-in-the-national-institute-for-health-research/2739>

- **Taking on the challenge: shaping health services through young people's participation**

Inspired by the work being done by child and adolescent mental health services (CAMHS) participation projects across the country, this ebook captures the 17 best examples of young people's participation across all health services.

<http://www.myapt.org.uk/year-4/gift-launches-ebook-with-nhs-england/>

- **The BMJ**

The BMJ launched a patient partnership strategy in 2014. The strategy promotes patient involvement within the journal itself as well as advocating patient involvement in the wider healthcare setting.

<http://www.bmj.com/campaign/patient-partnership>

6.4. Videos created by young people talking about involvement in research

- **INVOLVE**

Animated film by Tom Grew about his experience with Hodgkins lymphoma diagnosed aged 18 years and subsequent involvement in research.

<http://www.invo.org.uk/thisismystory/>

- **KidsCan, University of British Columbia, BC Children's Hospital and the Child & Family Research Institute in Vancouver**

KidsCan is a youth research engagement initiative which directly involves youths aged 14-17 as advisors and partners in the research and development of innovative mobile-based solutions to the health challenges they face. They are active participants in transferring scientific knowledge from clinicians and engineers to young people, rather than being passive receivers of knowledge.

<https://www.youtube.com/watch?v=YtyJ6DdkqKM>

- **National Children's Bureau**

NCB's young research advisors contribute their views on various research topics. This video explains the role they play and how they help the NCB Research Centre to see research subjects from a young person's perspective (2012).

<https://www.youtube.com/watch?v=Be97b8Ulk8M&feature=youtu.be>

- **Nuffield Council on Bioethics**

This clip shows highlights from a film produced by Helter Skelter Media for the Nuffield Council on Bioethics. It shows young people discussing the ethics of research studies involving children, during workshops held at a junior school, a secondary school, and a sixth form college in the autumn of 2013.

<https://www.youtube.com/watch?v=aJfS3GPehyk>

- **Theatre of Debate, 'People are Messy'**

'People are Messy' by Judith Johnson is a creative way to show why it is important to involve patients and people in research.

<http://www.theatreofdebate.co.uk/People-Scene-5.html>

More videos can be found here:

<http://www.theatreofdebate.co.uk/People/Scenes/People-are-Messy-Scenes.html>

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