

## **BANNAR Guidance for Involvement of Young People in Rheumatology Research**

### **Interim Statement**

#### **Background**

The involvement of young people in research is an important ethical imperative (UNCRC 1998) and has been called for by young people themselves (RCPC 2005). '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 including research priority and question setting, project development, advisory board membership, virtual user groups, co-researcher roles through to dissemination of results.

#### **BANNAR Young people Underpinning Rheumatology Research YOURR project**

Aims:

- (i) To identify the themes and topics which are important from a young person's perspective which will be used to refine and prioritise the future research strategy of the BANNAR
- (ii) 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
- (iii) To determine how and when young people want to be involved in the research process itself from agenda setting through to dissemination
- (iv) To develop a youth-led involvement strategy which will ensure their meaningful involvement in future research programmes of the BANNAR

However, until the results of this research is known, interim guidance to ensure safe, ethical and meaningful involvement of young people in rheumatology research has been requested by BANNAR members. The following has been compiled from existing resources (see appendix) which have been identified in the scoping exercise component of the YOURR project.

#### **General Considerations when involving young people in your research:**

##### *Planning and supporting involvement*

1. It takes considerable resource to set up and establish a young people's group, so bear this in mind before launching into setting one up.
2. 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!
3. 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.
4. It is best to recruit continuously and offer further opportunities, if possible, when young people get older and "age-out" out of group- e.g. adult advisory groups, volunteering opportunities etc.
5. Consider how to maximise accessibility, safety and ethical standards.

##### *Approach to involvement*

1. **Be flexible** in your approach - often it is more productive to have a mix of short and long term aspirations to maintain engagement.
2. **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.
3. Show young people that senior researchers are really interested in hearing their views and will take them seriously
4. 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.
5. 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.
6. 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 there are often no immediate tangible benefits. Also not all ideas or projects will succeed or be feasible or practical.

### **Guidance on involvement of young people**

#### **When planning involvement:**

- **Develop a plan for involving young people which considers:**
  - *What the existing evidence is for what young people think about the issue being studied*
  - *Why young people are and should be 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 and is NOT non-participation (ie tokenism, decoration, manipulation. (RCPCH Not Just a Phase (2010))
- Develop a clearly documented involvement plan which highlights how and why the 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.
- Consider the target age group of the project and developmental social interactions of different ages across the adolescent (10-19 years) and young adult (15-24 years) spectrum. For example, a project which spans the adolescent and young adult spectrum may consider holding two focus groups for 10-15 years and 16-24 years
- Depending on the project and feedback from young people themselves it may be appropriate to also hold a parental focus group, which may be done in parallel to the young adolescent focus group, if personnel and facilities allow

### **Facilitator**

- Identify a staff member with the necessary skills to effectively facilitate the involvement. They should be responsible for 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.

### **Role of Chair of 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.
- 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 to accommodate their long term conditions and acknowledging the attention spans of young people. Ensure young people have enough time to formulate and/or express their opinion.

#### **Post-activity 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.
- Consider offering 'token of thanks' if possible to further acknowledge their time and input e.g. Voucher for iTunes or Amazon

#### **References:**

- (i) Kirby, P (2004) *A guide to Actively Involving Young People in Research*. INVOLVE
- (ii) McDonagh JE, Bateman B. Nothing about us without us. Considerations for research involving young people. *Arch Dis Child Educ Pract Ed*. 2012;**97**:55-60
- (iii) Newman, J; Madge, N; Callens, C; Tibbins, C (2012) *Medicines for Children: reflecting on how young people improve research in this area. The Active Involvement of Children and Young People in Health and Social Care Research*. (Routledge)
- (iv) Royal College of Paediatrics and Child Health and Young Persons Health Special Interest Group. *Not Just a Phase. A guide to the participation of children and young people in health services*. (2010) [http://www.rcpch.ac.uk/system/files/protected/page/RCPCH\\_Not\\_Just\\_a\\_Phase\\_0.pdf](http://www.rcpch.ac.uk/system/files/protected/page/RCPCH_Not_Just_a_Phase_0.pdf)
- (v) Shaw C, Brady LM, Davey C. Guidelines for Research with Children and Young People (2011) <http://www.ncb.org.uk/what-we-do/research/involving-children-and-young-people-in-research>

**Websites:**

Participation Works [www.participationworks.org.uk](http://www.participationworks.org.uk)

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

NIHR <http://generationr.org.uk/>

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Date of Next Review: with BANNAR Youth Advisory Panel after completion of YOURR project 2015-2016