## The Scottish Children’s Research Network (ScotCRN) Young Persons Group

### Background, aims and objectives

The benefits of patient and public involvement (PPI) in research have been well documented. There are many ways the public and patients can be involved in the research process, as lay members on steering groups, management boards and in various aspects of the prioritisation, design and delivery of clinical trials. Hence ScotCRN, decided to establish a PPI with Young People of senior school age (11-18yrs ) to act as representatives of and advocates for children under 16yrs, participating in research and clinical trials. Specific tasks were to:

- Comment on the language, terminology, design and content of information sheets, questionnaires and other research tools.
- Raise awareness of clinical research in children young people and their parents aimed at increase availability and efficacy of medicines and health care in children.
- Provide opinions on research methods, on ethics, on methods of contacting or approaching young people and provide a pool of young people for focus groups.
- Determine the appropriateness and effectiveness of research tools.
- Influence content and design of proposed research.
- Ensure that all clinical trial documentation however complex, communicates the required information effectively to participants and their parents or carers.

### Initiation

Young people were invited from secondary schools in Aberdeen city and Shire to an Open Day held within the Royal Aberdeen Children’s Hospital (RACH). Invitations were made through head teachers and guidance teachers, highlighting the potential interest to those wanting to pursue a career in nursing, pharmacy, medicine or health care. Specialist children’s nurses were also asked to send invitations to patients and families attending hospital clinics. Posters and leaflets were sent to the schools, and posted in hospital waiting rooms, advertising the open day. From feedback with the Young People that attended, the schools did not display the posters as requested although guidance teachers had passed the information to the pupils they considered would be interested i.e. those who had indicated a desire to study medicine or professions allied to medicine. An advertisement was also placed in the University Staff Bulletin Board.

The Open Day was on a Saturday and advertised as an informal information day, with a series of short interactive lectures on ‘The discovery and development of paediatric medicines’, ‘Licensing of new medicines’, ‘The Role of ScotCRN’’ and ‘What being a member of ScotCRN YPG would mean’. At the conclusion of the day, the young people were given a thankyou pack containing a ScotCRN branded pen, a USB flash drive, an information sheet for parents, an application form to become a member, consent forms and contact details.

Of the 42 children and young people that attended, 41 registered their interest and of those 25 were selected to become members. The group were selected to ensure representation amongst the full range of ages and both sexes.

**Meetings**

At the first meeting the group were introduced to each other and asked to perform several 'ice breaker' tasks. These encouraged the members to introduce themselves to the group, find out information about each other and generally to move around the room and interact. They worked together to design a logo and name for the group. Since this initial meeting subsequent meetings have been held on an as required basis or at intervals no longer than 2 calendar months apart. The latter considered essential in order to maintain the interest and commitment of group members.

Each meeting includes a training session on an aspect of regulatory research governance, clinical trial design or medicine development and licensing. Although the group are representatives of young people who participate in trials we considered that it was important that they received relevant training in order to help them make informed decisions about the content of information sheets and other research materials whilst cognisant of current regulatory requirements. As the meetings are several weeks apart we have revision sessions in the format of quizzes, or games to revisit topics. Interactive demonstrations and tasks are used to illustrate terms and processes such as randomisation, blinding, un-blinding and placebo.

**Activities**

As awareness of the group has increased amongst the clinical research community in Scotland the activities of the group have become more varied. Many activities involve assessing the content and design of research support literature such as Patient and Parent information sheets, consent forms and posters. The language used in research tools and documents that are required to communicate complex information to children and their parents should be clear, convey a clear message and be age appropriate. The YPG assess the language and terminology used, if the required messages are clearly conveyed, if the design and content is appropriate for the target audience and suggests changes to the text and design. The group have commented on:

- Content of information sheets and consent and assent forms for parents and patients for clinical trials
- Content and art work for information sheets and consent forms for tissue bio banks,
- Content of questionnaires and incentives to encourage young people to complete questionnaires
- Patient trial diaries and the advantages/disadvantages of electronic versions.

Researchers and clinicians have attended the YPG to obtain their opinions on:

- The proposed national UK guidance for researchers on the content of information sheets for clinical trials
- The possible use of a smart ‘phone and tablet app for preschool children with autism
- How transition clinics should be managed for children who are participants in long term studies that involve a move from paediatric to adult clinical research facilities and teams

The YPG have also participated in focus groups for a long term cohort study, to discuss methods of increasing public participation and retention of young adults to the study and on their views on pharmaco-vigilance and the accessing of routinely acquired health data. Their contribution to the latter was used as part of a presentation at the British Science Festival 2012.

In addition to these organised activities the group contributes to content of the ScotCRN-YPG area of the website and have produced art work to be displayed in the clinical research facility in the hospital http://www.scotcrn.org/young-people/

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**Practical aspects -**

Meetings are planned to ensure a balance between enjoyable and informal activities and comments and opinions on research issues. Name badges are provided at each session for YPG members, visiting researchers and staff. Staff and visiting speakers participate in ice breaker sessions which we have found makes adults more approachable and involved. Light refreshments are available throughout. The timing of the agenda is flexible so that if interest and participation appear to reduce, or a task takes less time than expected, the facilitator can suggest an alternative activity such as a game, quiz or ice breaker.

When the task involves asking the group for opinions and comments, the group is broken down in to smaller groups of three or four members, with one member acting as a rapporteur with the responsibility of feeding back to the larger group. We have found that this is the most effective way of obtaining opinions or comments from all members. Rapporteurs collate their comments on flip charts or ‘post it’ notes to feedback to the larger group.

Visiting researchers and clinicians are encouraged to ensure that the questions they ask of the group are open and that they do not lead the discussion. Young people offer a different perspective on questions that should be asked and what is relevant to young people and hence should not be predetermined by the researcher. It is important that the members see the results of their input i.e. any changes to documentation or protocols following their comments. This reaffirms that their participation is meaningful and not tokenism and that it can result in real changes to research documentation.

"Ice breakers" that involve verbal and physical tasks, such as finding information, researching about each other or working in small groups to construct a model encourage involvement and are useful at the beginning and end of each meeting even when the group are well acquainted with each other.

As lunch-time can be awkward for new members or quieter members of the group we combine it with a group task or activity. We offer a range of finger foods, pizza, fruit and biscuits and keep lunchtime fairly short. The members receive a £20 voucher for attendance which covers their travelling expenses and includes a small recognition for their time. Feedback is obtained about the organisation, the food, the tasks, the ice-breakers and suggestions for the future.

**Maintenance and future plans**

At the end of the school year 5 of our 25 members left school and accordingly graduated from the YPG. Four new members who were aware of the group via friends, siblings or specialist nurses, applied to join, this has maintained the age and gender balance of the group. Over the first eighteen months of its existence the ScotCRN YPG membership has been consistent with approximately 20 attending each meeting.

The Aberdeen YPG of ScotCRN has been successful in retaining members, and bringing in activities that are relevant to the remit of the Network. Similar groups are planned in the other 3 main population centres of Scotland Edinburgh, Dundee and Glasgow.

However as can be seen from the range of activities and topics dealt with by the group significant support was required for its set up and will be required for its continuation. From the output to date this investment in time and money does appear to be well spent.