

NIHR Clinical Research Network

Young people participating in the design and promotion of RCT's.

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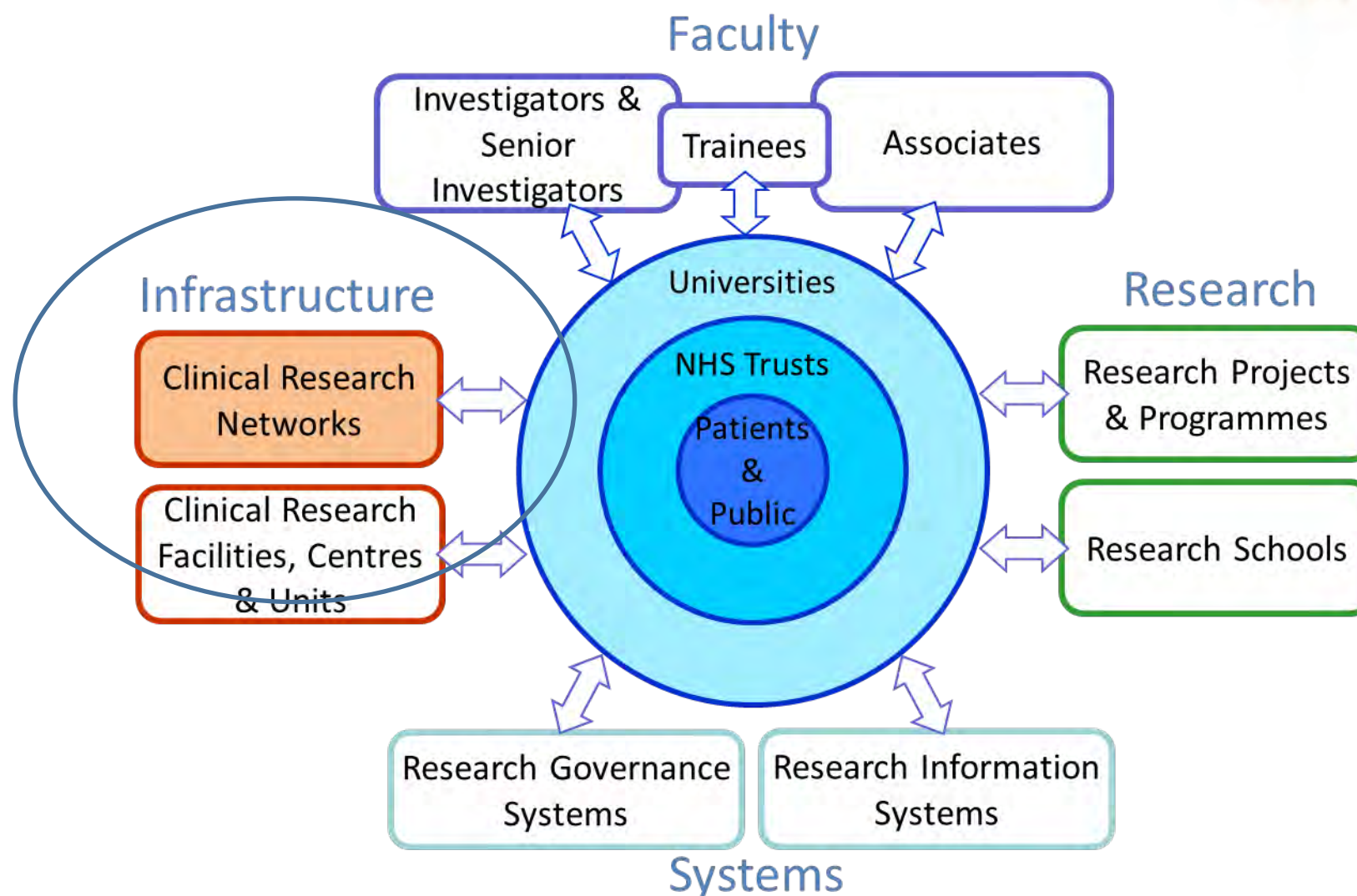
*Delivering clinical research to
make patients, and the NHS, better*

Involving young people

- Background
- National Young Persons Advisory Group (YPAG)
- The role of the group
- The importance of involving young people
- Some of the activities the group have been involved in



The NIHR Health Research System



Background





Young Persons Advisory Group



Role of the group

- **Learn** about health/clinical research in monthly meetings
- **support** and **work in partnership** with researchers in the delivery of health research
- **provide input** and **collaborate** with key organisations such as National Research Ethics Service (NRES), Royal College Paediatrics Child Health (RCPCH), NIHR Clinical Research Facilities (CRFs), R&D within NHS Trusts, Academic Health Science Networks (AHSNs) to promote the research agenda and more importantly the involvement and engagement of young people in their processes

Why is it important to involve young people

1

Adults often forget that children get bored and don't want to read a 7 page black and white leaflet

2

Young people can be put off participating or left feeling **confused** and **scared** if information isn't understandable

3

Adults shouldn't assume they know what young people want, we think differently

4

Some adults overlook how much vocabulary children understand, making leaflets too complicated or patronising

5

Young people's experiences in research must be listened to in order for the research to improve

6

We know what we do and don't want to know
- no information overloads!

To make research in young people for young people, you should involve young people and listen to what we want

Examples of YPAG and researchers partnership

1. Follow up study in children aged 6-8 years old:

Ensure outcomes children and young people felt were important are measured

Methods used are most suitable to children, young people and parents.

2. Asthma study:

Participant Information Leaflets (PILS) are designed to suit children and young people.

Feedback from researchers

“Generally, outcomes that the research team had already identified covered areas suggested; however, the research team added two new outcomes”. (Researcher, 2013)

“I’ve not run focus groups before and found this a useful exercise – I’ve proposed holding focus groups to help refine messages for the public / feedback from the completed research project (if funded)”. (Researcher, 2013)

Feedback from researchers

“The comments on what would be appealing and how to structure the leaflets for the younger age group has really helped”. (Researcher, 2010)

“The feedback I received was very useful and helped me with the layout and design, and helped me avoid anything that would have appeared confusing, unclear and which pictures to avoid”. (Researcher, 2011)



NHS
National Institute for
Health Research

You're invited to join us for

GenerationR

young people improving research



NHS
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Health Research

11th September 2013, Science Museum, London, 10am - 4pm

The award winning **NIHR Medicines for Children Research Network Young Person's Advisory Group** invite you to an event to showcase how **children, young people & families** have improved the design, development and delivery of paediatric research.

Topics led by Young People

Benefits of Collaborating with Children & Families
Impact & Evidence in the Design & Delivery of Research
Disseminating Research Results
The Future of Research / Educating the Next Generation

Special Guests

Professor Dame Sally Davies Chief Medical Officer
Sir Iain Chalmers Editor, James Lind Library
Simon Denegri Chair of INVOLVE
Dr Jonathan Sheffield CEO, NIHR Clinical Research Network

To register your interest please log on to
<http://sms.mcrn.org.uk/public/events/registration.aspx>



Garfield Weston
FOUNDATION

centre for the
developing brain



GenerationR
young people improving research



http://www.youtube.com/watch?v=KvamYWTDwQA&feature=em-upload_owner

Recommendations

Recommendation 1:

Work with key stakeholders including parents and young people to identify solutions on tackling the major challenges. This could be achieved in collaboration with organisations such as the Nuffield Council for Bioethics and the Royal College of Paediatrics and Child Health (RCPCH)

Recommendation 2:

Summary level results should be made publicly (open access) available for all clinical trials

Recommendation 3:

A patient specific (confidential) results feedback sheet mandatory part of the research process (as is the Patient Information Leaflet)

Recommendation 4:

We agree with the House of Commons Select Committee inquiry that peer review is vital to the reputation and reliability of scientific research and we agree that journal articles remain the primary instrument for the publication of summary-level trial results.

Continued....

Recommendation 5:

Researchers and sponsors should ensure provision for the on-going supply of a treatment shown to be successful in a clinical trial to the study participants

Recommendation 6:

To explore alternative and innovative ways of engaging with more young people and families, building our links with charitable organisations and parent/young people's groups

Recommendation 7:

MCRN PPI work-stream to work closely with the MCRN Children's Research Industry Group (CRIG) to explore how models of closer collaboration with industry partners can be implemented

Recommendation 8:

Build on collaborations with NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) to encourage involvement of young people and families in the identifying and prioritising of research studies

Continued....

Recommendation 9:

Develop an effective communications strategy that showcases involvement activities and sustains the objectives highlighted at GenerationR. This will require the use of innovative communication tools, such as; a dedicated GenerationR website, E-Magazine and the use of social media

Recommendation 10:

To develop a systematic way to measure the impact of involvement activities

Recommendation 11:

Work with the education sector to promote clinical research education in schools, sharing resources such as Testing Treatments Interactive, resources developed by NHS England, and Centre of the Cell.

Moving forward



For a full copy of the report and all key resources please click on the following link:

<http://viewer.zmags.com/publication/62b8f2e9>

Thank you!

Any questions?

IF YOU WOULD LIKE ANY FURTHER
INFORMATION ABOUT OUR YOUNG PEOPLES
INVOLVEMENT PLEASE CONTACT
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Children

