

Setting up a Young Person's Advisory Group

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The Medicines for Children Research Network is part of the National Institute for Health Research Clinical Research Network, which supports research to make patients, and the NHS, better

Overview of the presentation

- Why involve young people
- Patient and Public Involvement in the MCRN
- The role of the group
- What has the group been doing?
- How to set up a group
- Challenges
- Further Information



Why involve young people?

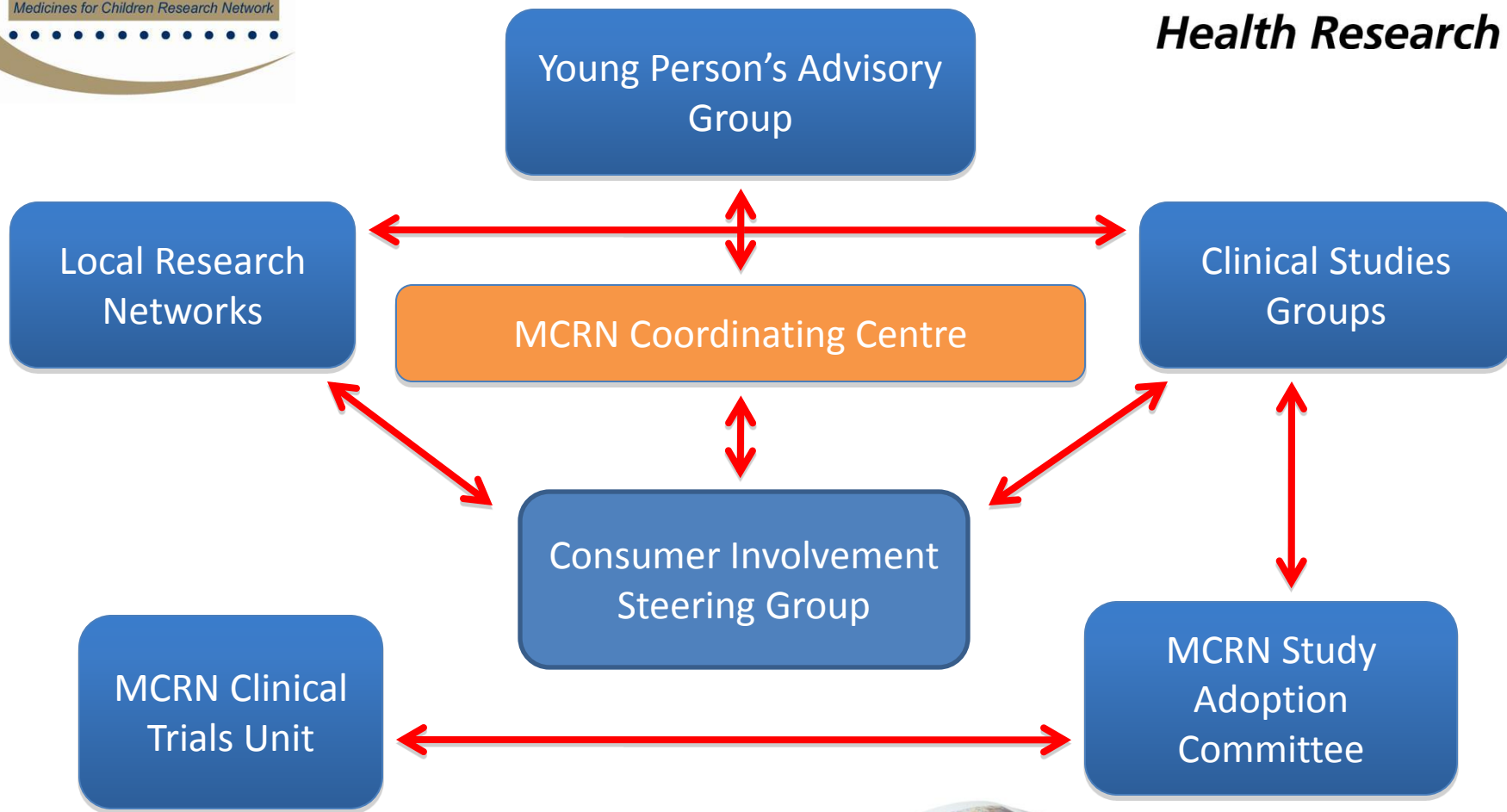
“High quality research, good accrual and retention rates, and improved outcomes for children, depend on listening to the voices of families and carers and, most importantly, children and young people themselves, and taking account of their experiences, priorities and perspectives”.

(MCRN Consumer Strategy 2012-2015)

“Adults need to listen to children & young people if the end result impacts on their lives”

“Children of all ages have opinions”

“Children & young people know how they want to be treated”





The Role of the Group

Learn about the MCRN and clinical research into Medicines for Children

Participate in MCRN activities, such as adapting documents on clinical trials so that they are suitable for children and young people

Contribute to research ideas and priorities

Contribute to the design of monitoring tools and schedules for children involved in clinical studies

Discuss and comment on aspects of research that might be important to outcomes of clinical trials and research

Disseminate information about the group as well as the MCRN and clinical research

Learn about research by carrying out mini projects or consultation activities



What Have We Been Doing?

What we young people want to know

NHS National Patient Safety Agency
National Research Ethics Service

Wasted Project @ The Bluecoat



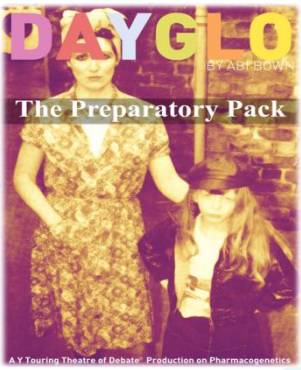
Working with Clinical Research Facilities

Ethical Guidance



Training & Education

investing in children



Designing posters for the new CRF

Outreach & Raising Awareness in the Community – Science Fairs, Conferences, School visits



How to set up a group

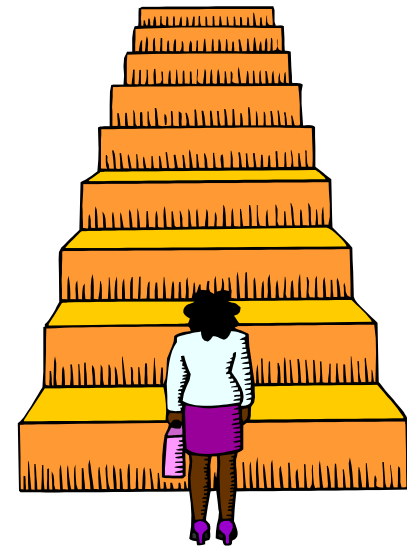
Considerations:

- Representativeness
- Working with gatekeepers
- Recruitment strategy
- Practical considerations
- Role of the group
- Training & support
- Resources



Challenges

- Time and resources
- Expertise
- Working with gatekeepers
- The need to accommodate different ages & abilities
- Retention
- Convincing researchers of the importance of involving young people
- Gaining feedback from researchers



Further Information



**The Medicines for Children
Research Network**

**Young Person's Advisory Group
Progress Report
2009-2011**



'The Medicines for Children Research Network is part of the NIHR Clinical Research Network - supporting research to make patients, and the NHS, better.'

www.mcrn.org.uk

- Handbook of service user involvement in nursing & healthcare research – case study MCRN Young Person's Group

- **Coming soon** (May 2012) - The Active Involvement of Children and Young People in Health and Social Care Research: Medicines for children: reflecting on how young people improve research in this area.





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**THANK
YOU!**
**Any
Questions?**

