Medicines for Children Research Network

Toolkit for Consumer Representatives on MCRN Clinical Studies Groups

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The NIHR Medicines for Children Research Network is part of the NIHR Clinical Research Network, which supports research to make patients, and the NHS, better.
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1. PURPOSE OF THE TOOLKIT

This Toolkit has been written by consumer members of National Institute for Health Research Medicines for Children Research Network (NIHR MCRN) Clinical Study Groups (CSGs) to provide practical guidance to other consumer members involved in the research processes of CSGs. These guidelines are suggestions based on consumers’ experiences working within the MCRN. This toolkit has been produced in parallel with another toolkit written for MCRN researchers on how to involve consumers in research.

Terminology

In this toolkit the term ‘Consumers’ refers to those who bring the views of people affected by childhood illnesses/conditions to the discussions, and specifically to parents/carers with experience of, or interest in, health conditions and/or health settings, including patients, young and old. The MCRN consumers are actively involved, or wishing to become involved, in the design of clinical research for children (rather than taking part as the ‘subjects’ of research).

2. BACKGROUND AND OVERVIEW OF THE NIHR MCRN

The NIHR was set up in 2005 and provides the framework through which the Department of Health can position, maintain and manage the research, research staff, and research infrastructure of the NHS in England as a National Research Facility.

Fig 1: Structure of the National Institute for Health Research

The MCRN is situated under infrastructure and is one of six topic specific clinical research networks which includes; cancer, stroke, diabetes, dementia and neurodegenerative diseases, and mental health. There is also a comprehensive research network which coordinates research outside of these topic areas and the Primary Care Research Network set up to focus on disease prevention, health promotion, screening, early diagnosis and the clinical management of long term conditions in the community.
The MCRN works in partnership with the NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC) to improve the UK’s clinical research environment and maximise the development of safe and effective medicines and formulations for children. The MCRN was created to improve the co-ordination, speed and quality of randomised controlled trials and other well designed studies of medicines for children and adolescents, including those for prevention, diagnosis and treatment.

The Coordinating Centre is based in the University of Liverpool’s Institute of Child Health at Alder Hey Children’s NHS Foundation Trust and led by Director, Professor Rosalind Smyth and Co-Director Dr William Van’t Hoff. The Coordinating Centre acts as a single point of contact for those conducting or interested in developing clinical studies.

The MCRN has six Local Research Networks (LRNs) to ensure that clinical trials involving children are performed efficiently to the highest standards across NHS sites. The networks cover over 100 NHS sites that serve approximately 6 million children. LRNs help with detailed feasibility assessments, assist with site selection and provide support with local financial, ethical and governance arrangements. In addition, LRNs can assist with staff recruitment and training, facilitate efficient recruitment of participants, monitor enrolment throughout projects and ensure that consumers are involved in local activities.

3. INVOLVING CONSUMERS IN MCRN ACTIVITIES:

All stages of the research process benefit from consultation with consumers, and the MCRN are adamant that children and families can make real contributions to decision-making in these areas. The MCRN is committed to the principle of healthcare professionals and public partnership throughout its work. We believe that high quality research with improved outcomes for children depends upon listening to the voices of children and young people, as well as their families and carers, and taking account of their experiences, priorities and opinions.

Over the past ten years, encouraging consumers to take an active involvement in health-related research has been highlighted as an NHS priority with their increased participation through the establishment of INVOLVE, the National Institute for Health Research (NIHR) and the NIHR Clinical Research Network.

Researchers and clinicians develop their expertise over many years of study and by putting their knowledge into practice in a clinical and/or research setting. However, they are unlikely to live with the condition or know every aspect of living with it for 24 hours each day. The social and psychological aspects of living with any chronic condition can create a different type of expertise to that of clinicians and researchers. Consumer involvement is concerned with creating a forum where the experience, knowledge and expertise of both healthcare professionals and the public can come together in partnership to benefit healthcare research.

Children and families actively involved in research need to be engaged through activities which have some impact on the research, with their views listened to and acted upon, to give effective and sustainable consumer involvement.

Consumers can contribute to all aspects of clinical research, including:

- Identifying and prioritising research topics
- Developing a grant application alongside professionals
- Designing and managing research
- Undertaking the research
- Analysing research data
- Disseminating research findings
One of the ways for you, the consumer, to be actively involved and contribute to all aspects of clinical research is through the MCRN Clinical Studies Groups (CSGs). They are led by enthusiastic individuals with outstanding track records of initiating and leading high quality studies of medicines for children, supported by members who may be specialist clinicians, consumers, research nurses and formulation scientists. This is the list of CSGs (June 2011):

- MCRN/BPAIIG Allergy, Infectious Diseases and Immunity
- Anaesthesia, Pain, Intensive Care and Cardiology
- MCRN/BSPED Diabetes, Endocrinology and Metabolic Medicine
- MCRN/UK Paediatric Gastroenterology, Hepatology and Nutrition
- General Paediatrics
- Methodology
- MCRN/AMR Neonatal
- MCRN/BAPN Paediatric Nephrology
- MCRN/UK LSD Inherited Metabolic Disorders
- Neurosciences
- Pharmacy and Pharmacology
- Respiratory and Cystic Fibrosis
- MCRN/Arthritis Research UK Paediatric Rheumatology

**CSG Membership and meetings**

Each of the CSGs is set-up by the MCRN with a defined system of membership rotation and a transparent appointment process for new Chairs and Members.

- The CSGs differ in their size of membership and balance of specialities within them.
- Each CSG has a number of members including clinicians, consumer representatives, research nurses, pharmacists and Formulation Research Fellows.
- Several CSGs have subgroups, working parties or related topic specific groups which are open to individuals who are not necessarily members of the parent CSG.
- CSGs meet twice a year face-to-face with additional teleconferences as required.
- Some CSGs have established partnerships with charities working in the same field who also attend CSG meetings and teleconferences.

**Role and remit of CSGs**

CSGs have two main roles, a development role and an advisory role:

The development role is a proactive approach (see fig 3)

- To identify gaps in research within speciality areas and determine relevant research priorities.
- To evaluate and support the development of clinical trials or other well designed studies to address research gaps.
- To participate in strategic decisions of the MCRN through representation on the MCRN Board.
Fig 3: Key Points in the Study cycle: The Development Role of Consumers' on CSGs

The advisory role is a reactive approach (see fig 4):

- To provide advice to investigators for the further development of research proposals and funding applications.
- To provide advice to commercial companies through the MCRN Industry Liaison Team.
- To advise the MCRN Study Assessment Committee regarding the quality of studies submitted to run through the network.

Fig 4: Key Points in the Study Cycle: The Advisory Role of Consumers’ on CSGs
4. GETTING STARTED

Below is a description of each stage of the research cycle and how consumers can contribute at each stage. You may be asked to be involved in one aspect or all depending on the CSG you are involved in. Always ask for feedback and check that your contributions and concerns have been discussed and addressed (record and feedback any problems as soon as they arise).

Identifying and prioritising research topics

This is one of the most important areas where you as a CSG member can contribute to what will or can be researched through your group’s research priority setting (included in the CSG’s Clinical Research Strategy document). This document aims to outline the key clinical research priorities that will change clinical practice in the CSGs disease area. It includes a comprehensive portfolio of key research priorities for clinical trials and related studies covering the entire spectrum of major disease areas of the CSG. This document includes a “Consumer Research Priorities” section in which you should specify any additional activities of the consumers within the CSG.

Developing a grant application with researchers

Following the identification and priority setting exercise you may be asked to support and develop a grant application alongside potential researchers. You will need to consider the following:

- Does the application explain to potential funders what the research is proposing to do from the point of view of patients and their carers?
- Is the research relevant to patients and their families?
- Do you know of other ongoing research which is the same or very similar to the proposed research – discuss with the potential researchers if there is duplication.
- Are there any ethical problems that could arise and have they been commented on from a consumer perspective?
- Is it clearly documented how and where the results of the research will be publicised (so that it will be useful and accessible to clinicians and consumers)?

Assisting with the design of studies

Your involvement in study design should ensure that studies are relevant to the target population, and any barriers to participation are identified and resolved at the outset.

You will need to consider the following:

- Is the study relevant to patients and their families?
- Is the study likely to be able to recruit patients as planned?
- Is the proposed study design acceptable and achievable?
- Is the proposed study methodology appropriate and acceptable?

This consistent ‘sounding board’ approach may help to focus researchers on the practicalities of what they have in mind and what they are trying to achieve.

You will be asked to contribute to the wording in information materials to be used by patients and carers, including lay study summary information (used for funding submissions and ethics documentation).
The management of studies

Most studies will have a steering committee that meet at regular intervals during the life span of the study, which you may be asked to sit on. Your involvement with a study steering group can be useful during the design, conduct, analysis and dissemination processes, depending on your experience. Your consumer perspective can help to identify causes of recruitment shortfall or to suggest ways in which researchers might approach some sections of the community. You could also be invited to be a co-applicant on a research study. Chairs of committees should ensure that you are not the lone consumer voice and give appropriate support.

The analysis or interpretation of research results

If you are an experienced consumer with relevant specific skills, you may be able to help in analysis or interpretation of research results. This may be by consulting trial participants on emerging findings, discussing with reference or advisory groups, or participating in workshops or other consultation events to discuss initial findings with potential end users.

The dissemination of research results

You may be able to help spread the word throughout the community about the results of a local research study or about clinical research for children generally. If you have patient group contacts you may want to discuss issues with your peers or present findings to interested groups in the area or national events for charities.

You could develop accessible ‘lay’ summaries of findings and web-based information for parents and children, co-present findings at conferences and produce videos. This could include discussing your involvement in the research process as well as research findings. There are a range of involvement opportunities, so there should be an area to suit your abilities.

5. REVIEWSING RESEARCH DOCUMENTS

You may be asked to participate in the review of research documentation or to contribute to CSG documentation. There are many different types of documentation and you should always hold in your mind the following pointers below:

- Is there any parent/young person involvement or contribution to the study design? If not how could this be achieved?
- Is the study design ethically sound, (does the design protect the safety, dignity, rights and well-being of the people taking part, with appropriate informed consent procedures)?
- Is the study design/methodology appropriate and acceptable, and clearly explained?
- Would there be any areas of the study which you feel parents or children would have concerns about? How could these concerns be addressed?
- Does the research address an important and relevant question to patients and their families, and is it clear what they are trying to find out?
- Does the research fit in with the CSGs defined research/medicines priorities?
- Is the outcome measure relevant to families and is it meaningful?
- How will answering the questions of the study be beneficial to people with the health problem the study is addressing?
- Are there any concerns from a consumer point of view about the methods used in a study? Are they suitable for children and young people?
• Are there any areas of the research or documentation that require clarification?

You should be clear as to what format and to whom your comments should be returned, and what the review deadline is. Where there are multiple consumers within a group organise a process for your comments to be consolidated and reviewed amongst yourself to provide a consensus opinion. This can be done by one person collecting together all comments from the consumers, and then pulling them together to make one set of comments, or doing a circular review, i.e.: one person is the first reviewer who sends their comments onto the second reviewer, who then adds in their comments. The final person to add comments then sends the final set back.

Additional information is given below for the types of documents commonly reviewed within the MCRN by consumers.

Research Proposal
This is a document that gives an overview of a research project or study which is under development. It gives a short description of the science or reason behind the study, and information about how the study will be done, and what activities the study would include.

Lay Summaries (e.g.: for funding submissions)
This is a shortened description of a study (or one particular part of the research protocol) which has been written for non-scientific readers. It should be written in plain English, always be clear and logical. These summaries should be easily understood at the first careful reading and include an appropriate depth of information (not so over simplified that the relevance of the information is lost).

Research Protocols and Protocol Summaries
Research Protocol: This is a document that describes what a study or trial is trying to investigate, how the study will be done, describes what activities will be completed, how the activities will be done, how the information will be collected, what tests will be used on the data to see if the study has worked, and who will be doing all these things. The protocol document usually gives the background of the study, including the scientific or medical reasons why the study is being done.

Protocol Summary: This is a shortened version of the research protocol which gives a brief description of the study information.

By looking at the “background information” and the “trial objectives and purpose” sections of these documents, you can look closely at the study design to see if it is ethically sound, and if the research will address an important and relevant question.

These documents should provide clear step-by-step information about what will be done as part of the study, by whom and how. It is important to look closely at the parts of the document which covers these areas – particularly the “trial design”, the “selection and withdrawal of subjects”, the “treatment of subjects, the “assessments of efficacy and safety” so as to then comment on if the methods are suitable for children and young people, and if there are areas of concern which should be addressed.

Patient Information Sheet and Consent Forms
Patient and Carers Information Sheet: These give children and/or parent/carers information about the study to help them to decide whether to take part in the study or not. This will include information about the purpose of the study, that it is new and experimental, the treatments and how likely a patient is to receive each type of treatment available in the study, the activities of the study, any risks involved, any benefits, details of alternative treatment, compensation details, payments to the patient for expenses, it must explain that it is voluntary to take part in the study, who will see the information collected and have access to the patient’s medical records, how confidentiality will be kept, who to contact for further
information, how long the study will last, and how many others will take part. It should be written in simple, age appropriate language and there may be different versions for younger children, older children and adults.

**Patient and Carers Consent Form:** This is the form a patient and/or their legal representative sign and date to show that they have agreed to take part in the study. Again, it should be clear and written in plain English with age appropriate language and there may be different versions for younger children, older children and adults.

**MCRN CSG Clinical Research Strategy**
This document gives the specifics about what progress the CSG has made to date, what the group’s aims, remit and goals are, and specifies key clinical research priorities (developed through a detailed consultation process with all relevant stakeholders), which would contribute to changing clinical practice within the group’s area.

It is important to that you contribute by reviewing and commenting from a family’s perspective on all sections of this document. Also provide a specific consumer section within this strategy to highlight how and where consumers are contributing to the CSG processes.

**CSG Annual Report or Progress Report**
This document gives an overview of the activities and progress made within and by the CSG in the previous year including meetings, studies reviewed, studies adopted, activities relating to research applications submitted, links with pharmaceutical companies and charities along with activities planned for the forthcoming year. You need to check that the consumer activities are documented within the report.

6. CONSUMER INVOLVEMENT IN MEETINGS AND TELECONFERENCES

**Preparing for meetings**
- Identify points on the agenda that may be of particular interest and be prepared to discuss these at the meeting.
- Consider whether there are any sensitive areas of discussion and be prepared for the group to openly discuss them e.g. discussions about morbidity.
- Think about the consumer angle on all agenda items and try to think of what contributions you can give from a consumer perspective to each item.

**At the beginning of a meeting**
- Be ready to introduce yourself to the group – explaining your background and consumer perspective/experience that you bring.
- Ask members to use plain English or explain their jargon, abbreviations and acronyms as they go along.

**During the meetings**
- Ask questions if the item under discussion is unclear.
- Try to be ready to comment on issues other than just consumer items – be prepared to bring some of your other skills and experience to the discussions.
- Don’t be surprised if you are asked further questions about your views or are constructively challenged as part of an honest and respectful discussion about issues within the group.
• Don’t be surprised if there are members of the group who always discuss items together or sit together – always be prepared to put yourself forward to be part of these groups and discussions.

• Everyone within the group will want to put their views forward, so sometimes the meeting Chair may ask you to finish-up your point to allow another person to speak.

• The Chair will want to ensure that everyone has the opportunity to speak, so they may come to you to ask your opinion on a specific item.

• Try to vary your position around a meeting table – don’t feel you have to sit out on the edge of the group, nor always next to the Chair!

• For telephone conferences, always make sure you are on the telephone a few minutes early so you can listen to each person who joins the call so you know who has called into the meeting.

After a meeting

• Check the meeting minutes to ensure that your contributions are correctly noted. Also check for any action items you are responsible for.

• Don’t be afraid to give any feedback to the Chair about the meeting.

• Do ask the Chair any queries or for clarifications on items that were unclear (a short email is a great way to do this).

• Remember to ask for feedback from the Chair as to where your input has been particularly valuable, or ways in which your input could be made more effective.

7. ASSESSING THE IMPACT OF CONSUMER INVOLVEMENT

The MCRN assess the impact of consumer involvement on its research activities by obtaining feedback from consumers and researchers who have worked together, and collecting evidence of good and bad practice in consumer involvement.

You may be asked to give your feedback at a meeting, via a telephone conversation, by email or by completing a questionnaire (see Appendix 4). It is helpful if you ask for formal or informal feedback on an ongoing basis from the researchers on how your input may have changed the research, and how the process has gone (feedback may not always be positive!).
Appendix 1: Glossary of Research Terms

Abstract  This is a brief summary of a research study and its results. It should tell you why the study was done, how the researchers went about it and what they found.

Action research  Action research is used to bring about improvement or practical change. A group of people who know about a problem work together to develop an idea about how it might be resolved. They then go and test this idea. The people who take part in the testing provide feedback on their experiences. They may also identify further actions that need to be researched and tested. This cycle of developing solutions and testing them is repeated until the problem has been solved.

Advisory Group  Many research projects have an advisory group (or steering group). The group helps to develop, support, advise and monitor the project. The group often includes people who use services, carers, researchers and other health and social care professionals, who can provide relevant advice.

Analysis  Data analysis involves examining and processing (data analysis) research data, in order to answer the questions that the project is trying to address. It involves identifying patterns and drawing out the main themes, and is often done with specialist computer software.

Audit  An audit of health or social care involves carrying out a systematic assessment of how well that care is being delivered. Current policy and practice is compared with an agreed standard, so that any problem areas can be identified and improved. Later, the audit can be carried out again to check that the changes made have actually made a difference.

Basic research  Basic research aims to improve knowledge and understanding, rather than finding a solution to a practical problem. It usually involves work in a laboratory – for example to find a gene linked to a disease or to understand how cancer cells grow. This kind of research can sometimes provide clues as to which avenues to explore to develop new treatments.

Carer  A carer is a relative, friend or partner who provides (or intends to provide, or used to provide) a substantial amount of care to another person on a regular basis, but not necessarily through living with them.

Clinical research  Clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes comparing them with healthy people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records, or the data from health and lifestyle surveys.

Clinical trial (trial)  Clinical trials are research studies involving people who use services, which compare a new or different type of treatment with the best treatment currently available. They test whether the new or different treatment is safe, effective and any better than what already exists. No matter how promising a new treatment may appear during tests in a laboratory, it must go through clinical trials before its benefits and risks can really be known.

Collaboration  Collaboration involves active, on-going partnership with members of the public in the research process. For example, members of the public might take part in an advisory group for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project.

Commissioner  A commissioner is the person (or organisation) who asks for a piece of research to be carried out.

Commissioning  Commissioning usually involves: identifying funding for a piece of research, preparing a research brief, advertising the research topic, selecting a shortlist of researchers who apply to undertake the research, arranging for proposals to be peer reviewed, making a decision about which researchers are going to be awarded the funding and agreeing a contract.
**Commissioning Board/Commissioning Panel** A Commissioning Board is a group of people who oversee the commissioning process. It is made up of research funders, researchers, health and/or social care professionals and often includes people who use services and carers.

**Confidentiality** During a research project, the researchers must put data protection measures into place, to ensure that all of the information collected about the participants is kept confidential. This means that the researchers must get the participants' written permission to look at their medical or social care records. It also means that any information that might identify the participants cannot be used or passed on to others, without first getting the participants' consent. For example, when researchers publish the results of a project, they are not allowed to include people's names. This confidentiality will only be broken in extreme circumstances: where it is essential for the person's care, treatment or safety, where it is required by a court order, e.g. in a criminal investigation, or it is necessary to protect the public.

**Consultation** Consultation involves asking members of the public for their views about research, and then using those views to inform decision-making. This consultation can be about any aspect of the research process – from identifying topics for research, through to thinking about the implications of the research findings. Having a better understanding of people's views should lead to better decisions.

**Consumer** The term consumer is used to refer collectively to: people who use services, carers, organisations representing consumers' interests, members of the public who are the potential recipients of services, groups asking for research to promote good health or because they believe they have been exposed to potentially harmful circumstances, products or services.

**Data** Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others, e.g. in reports, graphs or diagrams.

**Data protection** All personal information is protected in the UK by the Data Protection Act (1998). This means that researchers have to put in all the necessary safeguards to protect the confidentiality of the information they collect about research participants. They should explain in the patient information sheet: how the participants' data will be collected, how it will be stored securely, what it will be used for, who will have access to the data that identifies participants, how long it will be kept and how it will be disposed of securely.

**Dissemination** Dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through: producing reports (often these are made available on the Internet), publishing articles in journals or newsletters, issuing press releases and giving talks at conferences. It is also important to feedback the findings of research to research participants.

**Emancipatory research** With emancipatory research, people who use services, rather than professional researchers, have control of the whole research process. They plan and undertake the research, and interpret the findings. The main aim is always to empower people and improve people's lives. 'Professional' researchers may be brought in as advisers or have specified roles within the project.

**Empowerment** This is the process by which people who use services equip themselves with the knowledge, skills and resources they need to be able to take control over decisions and resources. It often involves people building confidence in their own strengths and abilities. It does not always mean people take control over all decisions or all resources.

**Ethics** Ethics are a set of principles that guide researchers who are carrying out research with people. Ethical principles are designed to protect the safety, dignity, rights and well-being of the people taking part. They include the requirement to ask each individual to give their informed consent to take part in a research project.
Ethics Committees The job of an ethics committee is to make sure that research carried out respects the dignity, rights, safety and well-being of the people who take part. Increasingly Ethics Committee approval is needed for health and social care research. Ethics committee members include researchers and health care professionals as well as members of the public.

Evaluation This involves assessing whether an intervention (for example a treatment, service, project, or programme) is achieving its aims. A project can be evaluated as it goes along or right at the end. It can measure how well the project is being carried out as well as its impact. The results of evaluations can help with decision-making and planning.

Evidence Base An evidence base is a collection of all the research data currently available about a health or social care topic, such as how well a treatment or a service works. This evidence is used by health and social care professionals to make decisions about the services that they provide and what care or treatment to offer people who use services.

Experimental This type of research allows researchers to explore Research cause and effect. For example, experimental research would be used to see whether a new drug is effective in reducing blood pressure. The research design (in this example a randomised controlled trial) will tell the researcher whether any reduction in blood pressure is definitely due to the drug.

Experts by experience The term ‘experts by experience’ refers to service users and carers, who are experts through their experience of illness or disability and services.

Focus Group A focus group is a small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.

Grey Literature Grey literature is material that is less formal than an article in a peer review journal or a chapter in a book – so it’s not easily tracked down. It includes internal reports, committee minutes, conference papers, factsheets, newsletters and campaigning material. However, ‘grey literature’ may be made available on request and is increasingly available on the Internet.

Honorary contract Honorary contracts are required by anyone who wants to carry out research or observe people in an NHS setting, but who does not already have an employment contract or a volunteer contract with the relevant NHS Trust. The contract ensures that they are covered by NHS liability insurance, and that they are contractually bound to take proper account of the NHS duty of care.

Implementation Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.

Intervention An intervention is something that aims to make a change and is tested through research. For example, giving a drug, providing a counselling service, improving the environment or giving people information and training are all described as interventions.

Interview In research, an interview is a conversation between two or more people, where a researcher asks questions to obtain information from the person (or people) being interviewed. Interviews can be carried out in person (face-to-face) or over the phone.

Involvement Involvement in research refers to active involvement between people who use services, carers and researchers, rather than the use of people as participants in research (or as research ‘subjects’). Many people describe involvement as doing research with or by people who use services rather than to, about or for them.

Journal A journal is a regular publication in which researchers formally report the results of their research to people who share a similar interest or experience. Each journal usually specialises in one particular topic area. The BMJ (British Medical Journal), British Journal of Social Work and The Lancet are examples of journals.

Lay (lay person) The term lay means non-professional. In research, it refers to the people who are neither academic researchers nor health or social care professionals.
Lay summary A lay summary is a brief summary of a research project or a research proposal that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included.

Members of the public (or public) This term includes: patients and potential patients, people who use health and social care services, informal (unpaid) carers, parents/guardians, disabled people, members of the public who are potential recipients of health promotion programmes and/or public health programmes and/or social service interventions, groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos), organisations that represent people who use services.

Mentor A mentor is a person willing to share their experience, knowledge and wisdom to help, guide and support someone who is less experienced. Mentors act as friends, teachers and advisers. A person who is newly involved in research can ask for a mentor to help them adjust to their new role.

Methodology The term methodology describes how research is done – so it will cover how information is collected and analysed as well as why a particular method has been chosen.

Monitoring research Monitoring research involves keeping up to date with the progress of a research project. This will include ensuring that the researchers are carrying out their research according to their research proposal or protocol, that the research is keeping to time and budget and that the research is being conducted ethically.

NHS research NHS research is research carried out in the NHS or funded by the NHS. This includes research that takes place in local hospitals or GP surgeries, and larger studies commissioned by the NHS at a national level, for example: a study based in a GP surgery looking at people’s experience of long-term chronic pain or a randomised controlled trial to look at the best treatment for people with bowel cancer.

Outcome measures Outcome measures are measurements of the effects of a treatment or service. They might include physical measurements – for example measuring blood pressure, or psychological measurements – for example measuring people’s sense of well-being. So if someone takes part in research, they may be asked questions, or may be asked to have extra tests to assess how well the treatment or service has worked.

Participant A participant is someone who takes part in a research project. Sometimes research participants are referred to as research ‘subjects’.

Participatory research This is a type of research where researchers and people who use services or carers are partners in a research project. The research addresses an issue of importance to service users or carers, who are involved in the design and conduct of the research, and the way the findings are made available. The aim of the research is to improve people’s lives. This isn’t a research method – it’s an approach to research, a philosophy.

Patient information leaflet/patient information sheet Researchers must provide a patient information leaflet to everyone they invite to take part in a research study, to ensure people can make an informed decision about this. The leaflet explains what taking part will involve and should include details about: why the research is being done, how long it will last, and what methods will be used, the possible risks and benefits, what taking part will practically involve, e.g. extra visits to a hospital or a researcher coming to interview someone at home, what interventions are being tested, or what topics an interview will cover, how the researchers will keep participants’ information confidential, what compensation is available to people if they are harmed as a result of taking part in the research who to contact for further information and how the results will be shared with others.

Peer review/refereeing Peer reviewing is where a research proposal or a report of research is read and commented on by people with similar interests and expertise to those who wrote the proposal or report. Peer reviewers might be members of the public, researchers, or other professionals. Peer review helps to check the quality of a report or research proposal.
Members of the public who act as peer reviewers may choose to comment on: whether the research addresses an important and relevant question, the methods used by researchers, the quality of public involvement in the research.

**Peer interviewing** Peer interviewing is where people are interviewed by others who have a similar experience to them – their peers. For example, in a project to find out about children’s experiences of after school care, children with experience of using after school care may act as peer interviewers, asking other children about their experience. Some researchers believe that this kind of interviewing enables people to talk more freely about their experience.

**Perspectives/user perspectives** A user perspective is often what people with experience of using health or social services are asked to bring when they get involved in research. They are asked to provide ideas, comments and suggestions based on the unique insight they have from their knowledge and experience of life with a health condition. They cannot be representative of everyone who uses a particular service, but they can offer their own perspective, and often that of other people.

**Placebo** A placebo is a fake or dummy treatment that is designed to be harmless and to have no effect. It allows researchers to test for the ‘placebo effect’. The placebo effect is a psychological response where people feel better because they have received a treatment, and not because the treatment has a specific effect on their condition. By comparing people’s responses to the placebo and to the treatment being tested, researchers can tell whether the treatment is having any real benefit.

**Protocol/research protocol** A protocol is the plan for a piece of research. It usually includes information about: what question the research is asking and its importance/relevance, the background and context of the research, including what other research has been done before, how many people will be involved, who can take part, the research method and what will happen to the results and how they will be publicised. A protocol describes in great detail what the researchers will do during the research. Usually, it cannot be changed without going back to a research ethics committee for approval.

**Public health research** Public health is concerned with promoting good health, preventing disease and protecting people from hazards, rather than treating illnesses. It covers topics like the control of infectious diseases, vaccinations, and helping people to adopt healthy lifestyles. Public health research involves finding out new knowledge (or testing out existing ideas) to do with public health – so it might address questions about: the best ways to help people stop smoking or how Bird Flu spreads.

**Qualitative research** Qualitative research is used to explore and understand people’s beliefs, experiences, attitudes or behaviours. It asks questions about how and why. Qualitative research might ask questions about why people want to stop smoking. It won’t ask how many people have tried to stop smoking. It does not collect data in the form of numbers. Qualitative researchers use methods like focus groups and interviews (telephone and face-to-face interviews).

**Quantitative research** In quantitative research, researchers collect data in the form of numbers. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year, or what proportion of children have had an MMR vaccine, or whether a new drug lowers blood pressure more than the drugs that are usually used. Quantitative researchers use methods like surveys and clinical trials.

**Questionnaire** A questionnaire is a prepared set of written questions used to obtain information from research participants. Questionnaires can be completed on paper, using a computer or with an interviewer.

**Randomised controlled trial** A controlled trial compares two groups of people: an experimental group who receive the new treatment and a control group, who receive the usual treatment or a placebo. The control group allows the researchers to see whether the treatment they are testing is any more or less effective than the usual or standard treatment. In a randomised controlled trial, the decision about which group a person joins is random (i.e. based on chance). A computer will decide rather than the researcher or the participant.
Randomisation ensures that the two groups are as similar as possible, except for the treatment they receive. This is important because it means that the researcher can be sure that any differences between the groups are only due to the treatment.

**Representative** As a representative, you are expected to speak on behalf of a larger group of people. If you’ve been asked to get involved in research as a representative of a particular group, you may want to think about how you can be confident that you are representing a wider range of people’s views, rather than just offering your own perspective.

**Research** The term research means different things to different people, but is essentially about finding out new knowledge that could lead to changes to treatments, policies or care. The definition used by the Department of Health is: “The attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods”.

**Research brief** Research commissioners write a research brief. The brief describes why they want to commission a piece of research, what questions the research should address and sometimes how the research should be carried out. It might include information about when the research needs to be completed and how much money is available. Researchers then write a research proposal that explains how they will address the research brief.

**Researcher** Researchers are the people who do the research. They may do research for a living, and be based in a university, hospital or other institution, and/or they may be a service user or carer.

**Research governance** Research governance is a process aimed at ensuring that research is high quality, safe and ethical. The Department of Health has a Research Governance Framework for Health and Social Care, which everyone involved in research within the NHS or social services must follow.

**Research grant** Research grants are given to enable researchers to carry out a particular piece of research. They might amount to millions of pounds for a major study about genetics for example, or a few hundred pounds for a local study about people’s experience of using a particular service. Usually, in order to get research grants, researchers have to write a research proposal and receive a positive peer review.

**Research methods or techniques** Research methods are the ways researchers collect and analyse information. So, research methods include interviews, questionnaires, diaries, clinical trials, experiments, analysing documents or statistics, and watching people’s behaviour.

**Research network** Research networks aim to bring together people who have an interest in research about a particular condition or group of people. Networks might be national or local. The Department of Health supports research networks to promote research in specific areas. These include: cancer, medicines for children, diabetes, dementia, mental health and stroke. These networks encourage researchers to work together and improve the quality of research. Outside the NHS there are other types of research networks. For example, the Alzheimer’s Disease Society and the Multiple Sclerosis Society support research networks of service users and carers who are actively involved in research.

**Research partner** The term research partner is used to describe people who get actively involved in research, to the extent that they are seen by their ‘professional’ colleagues as a partner, rather than someone who might be consulted occasionally. Partnership suggests that researchers and service users/carers have a relationship that involves mutual respect and equality.

**Research proposal** This is usually an application form or set of papers that researchers have to complete to say what research they want to do and how they want to do it. It will also cover the aim of the research, what the research questions are, who will be involved (both as participants and in carrying out the research), the time-scale and the cost. **Service user or user** A service user is someone who uses or has used health and/or social care services because of illness or disability. Some people do not like this term because they feel it has negative connotations.
Social care research Social care refers to a range of services provided across different settings, usually in the community. These include: home care, day care and residential care for older people, residential care and fostering for children, support for parents of disabled children, supporting mental health service users, physically disabled people and people with learning difficulties and support for carers. Social care research involves finding out new knowledge (or testing out existing ideas) to do with social care – so social care research might address questions about: people’s experience of using different home care services or the best ways to train new foster parents.

Statistics and Statistics are a set of numbers (quantitative data) statistical analysis obtained through research. For example, the average age of a group of people, or the number of people using a service. Statistical analysis uses a set of mathematical rules to analyse quantitative data. It can help researchers decide what data means. For example, statistical analysis can assess whether any difference seen between two groups of people (e.g. between the groups of people in a clinical trial) is likely to be a reliable finding or simply due to chance.

Survivor researcher Survivor is a term some people who have used health or social care services use to describe themselves – they see this as a more empowering term than ‘patient’ or ‘sufferer’. For example, some people who have used mental health services or who have experienced mental or emotional distress call themselves survivors of the psychiatric system. Some people who have recovered from cancer call themselves cancer survivors. If someone describes themselves as a survivor researcher, they are making a statement about the fact that they have used health or social care services as well as being a researcher.

Systematic review Systematic reviews aim to bring together the results of all studies addressing a particular research question that have been carried out around the world. They provide a comprehensive and unbiased summary of the research. For example, one clinical trial may not give a clear answer about the effectiveness of a treatment. This might be because the difference between the treatments being tested was very small, or because only a small number of people took part in the trial. So systematic reviews are used to bring the results of a number of similar trials together, to piece together and assess the quality of all of the evidence. Combining the results from a number of trials may give a clearer picture.

User controlled research/user led research is research that is actively controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. The service users will run the research advisory or steering group and may also decide to carry out the research. Some service users make no distinction between the term user controlled and user led research, others feel that user led research has a different, vaguer meaning. They see user led research as research which is meant to be led and shaped by service users but is not necessarily controlled by them. Control in user led research in this case will rest with some other group of non-service users who also have an interest in the research, such as the commissioners of the research, the researchers or people who provide services.

User researcher A user researcher is someone who uses or has used health and/or social care services because of illness or disability, who is also a researcher. Not all researchers who use health or social care services call themselves user researchers. Calling yourself a user researcher is making a statement about your identity as a service user as well as a researcher.

The items in Appendix 1 are from the Involve booklet: 4 Public Information Pack (PIP) – How to get actively involved in NHS, public health and social care research – Jargon Buster. http://www.invo.org.uk/pdfs/PIP44jargonbuster.pdf
Appendix 2: List of MCRN Terms, Abbreviations and Websites

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>AHP</td>
<td>Allied Health Professional</td>
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<tr>
<td>CSAC</td>
<td>Clinical Standards Advisory Group</td>
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<tr>
<td>CSG</td>
<td>Clinical Study Group</td>
</tr>
<tr>
<td>CI</td>
<td>Chief Investigator</td>
</tr>
<tr>
<td>CLRN</td>
<td>Comprehensive Local Research Network</td>
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<tr>
<td>CTU</td>
<td>Clinical Trial Unit</td>
</tr>
<tr>
<td>IRAS</td>
<td>Integrated Research Application System <a href="http://www.myresearchproject.org.uk">www.myresearchproject.org.uk</a></td>
</tr>
<tr>
<td>LREC</td>
<td>Local Research Ethics Committee</td>
</tr>
<tr>
<td>LRN</td>
<td>Local Research Network</td>
</tr>
<tr>
<td>NIHR</td>
<td>National Institute for Health Research</td>
</tr>
<tr>
<td>MCRN</td>
<td>Medicines for Clinical Research Network</td>
</tr>
<tr>
<td>MREC</td>
<td>Multicentre Research Ethics Committee</td>
</tr>
<tr>
<td>PI</td>
<td>Principal Investigator</td>
</tr>
<tr>
<td>TSG</td>
<td>Topic Specific Group</td>
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</table>

More abbreviations and acronyms can be found on the following website: [http://www.medilexicon.com](http://www.medilexicon.com)

MCRN coordinating centre: [www.mcrn.org.uk](http://www.mcrn.org.uk)

NIHR Clinical Research Network: [www.nihr.crn.org.uk](http://www.nihr.crn.org.uk)

Database of Uncertainties about the Effects of Treatments (DUETs): [http://www.duets.nhs.uk/](http://www.duets.nhs.uk/)
An open, on-line collection of uncertainties in treatment methods, collated from clinicians, researchers, patients and carers. Leads to prioritisation of uncertainties for research purposes (see James Lind Alliance also).

Folk-Us: folk.us@exeter.ac.uk A Dept of Health funded initiative to facilitate and promote effective involvement in North and East Devon.

INVOLVE: [www.invo.org.uk](http://www.invo.org.uk) National Advisory Group to promote and support public involvement in NHS, public health and social care research.

James Lind Alliance: [www.lindalliance.org](http://www.lindalliance.org) Established to bring patients and clinicians together to identify and prioritise unanswered questions in treatments. A focus on diabetes will take place during 2008 and 2009, with establishment of a DUETs Database for Diabetes.


Medical Research Council (MRC): [www.mrc.ac.uk](http://www.mrc.ac.uk) A publicly-funded organisation which funds and supports health research in the UK.

National Children’s Bureau (NCB): [www.ncb.org.uk](http://www.ncb.org.uk) Promoting the voices, interests and well-being of children, with a research department and a participation unit (for NCB projects).

National Institute for Health Research (NIHR): [www.nihr.ac.uk/](http://www.nihr.ac.uk/)
National Library for Health – Patient & Public Involvement Specialist Library: www.library.nhs.uk/ppi A library to support PPI across the UK.

NHS Centre for Involvement: www.nhscentreforinvolvement.nhs.uk Organisation to promote PPI in change within the NHS.

Patient-Citizen Exchange: www.pcx.nhs.uk Organisation to promote PPI activities in NHS organisations.

People in Research: www.peopleinresearch.org UKCRC project, led by INVOLVE, helping people make contact with those offering opportunities for active involvement.

Royal College of Paediatrics and Child Health (RCPCH)
Appendix 3: CSG Specific Abbreviations & Websites

### MCRN/Arthritis Research UK Paediatric Rheumatology CSG

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CHAM</td>
<td>Childhood Myositis Assessment Scale</td>
</tr>
<tr>
<td>CHAQ</td>
<td>Childhood Health Assessment Questionnaire</td>
</tr>
<tr>
<td>DAS</td>
<td>Disease Activity Score</td>
</tr>
<tr>
<td>DEXA Scan</td>
<td>Dual-energy X-ray absorptiometry, test that measures bone density</td>
</tr>
<tr>
<td>JDM</td>
<td>Juvenile Dermatomyositis</td>
</tr>
<tr>
<td>JDRC</td>
<td>Juvenile Dermatomyositis Research Centre</td>
</tr>
<tr>
<td>JDRG</td>
<td>Juvenile Dermatomyositis Research Group</td>
</tr>
<tr>
<td>JIA</td>
<td>Juvenile Idiopathic Arthritis</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging, scan using magnetic and radio waves</td>
</tr>
<tr>
<td>MTX</td>
<td>Methotrexate</td>
</tr>
<tr>
<td>SLE</td>
<td>Systemic Lupus Erythematosus</td>
</tr>
<tr>
<td>USS</td>
<td>Ultrasound Scan</td>
</tr>
<tr>
<td>VAS</td>
<td>Visual Analogue Scale</td>
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</table>

**Arthritis Care**: [www.arthritis-care.org.uk](http://www.arthritis-care.org.uk)

**Arthritis and Musculoskeletal Alliance (ARMA)**: [www arma uk.net](http://www arma uk.net)

**British Society of Paediatric and adolescent rheumatology (BSPAR)**: [www.bspar.org.uk](http://www.bspar.org.uk)

**British Society for Rheumatology (BSR)**: [www.rheumatology.org.uk](http://www.rheumatology.org.uk)

**Arthritis Research UK (ARUK)**: [www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

**Childhood Arthritis and Rheumatology Research Alliance (CARRA)**: [www.carragroup.org](http://www.carragroup.org)

**Children’s Chronic Arthritis Association** [www.cca.org.uk](http://www.cca.org.uk)

**Paediatric Rheumatology International Trials Organization (PRINTO)**: [www.printo.it](http://www.printo.it)

**Paediatric Rheumatology European Society (PReS)**: [www.pres.org.uk](http://www.pres.org.uk)

**Scottish Network for Arthritis in Children (SNAC)**: [www.snac.uk.com](http://www.snac.uk.com)

**Scottish Paediatric and Adolescent Rheumatology Network (SPARN)**: [www.sparn.scot.nhs.uk](http://www.sparn.scot.nhs.uk)

**Understanding Childhood Arthritis Network (UCAN)**:
MCRN/BAPN Paediatric Nephrology CSG

NFK UK National Kidney Federation

British Association for Paediatric Nephrology (BAPN):  www.bapn.org
British Kidney Patient Association (BKPA):  www.britishkidney-pa.co.uk
Cystinosis.Org.UK:  www.cystinosis.org.uk
Irish Kidney Association:  www.ika.ie
Kids Kidney Research (KKR):  www.kidskidneyresearch.org
The NephCure Foundation:  http://www.nephcure.org
Nephrotic Syndrome Trust (Nest):  www.nstrust.co.uk
UK Registry for Rare Kidney Diseases (RaDaR):  www.renalradar.org

MCRN/BPAIIG Allergy, Infectious Diseases and Immunity

XXX Abbreviations pending

American Academy of Allergy, Asthma and Immunity:  http://www.aaaai.org
American Society for Microbiology:  http://www.asm.org
British HIV Association:  http://www.bhiva.org
British Infection Society:  http://www.britishinfectionsociety.org
British Paediatric Allergy Immunology and Infection Group:  http://www.bpaiig.org
British Society for Immunology:  http://immunology.org
European Academy of Allergy and Clinical Immunology:  http://www.eaaci.net
European Society for Paediatric Infectious Diseases:  http://www.espid.org
Federation of European Microbiological Societies:  http://www.fems-microbiology.org/website/nl/default.asp
Hospital Infection Society:  http://www.his.org.uk
Infectious Disease Society of America:  http://www.idsociey.org
Primary Immunodeficiency Network:  http://www.ukpin.org.uk
Anaesthesia, Pain, Intensive Care and Cardiology

XXX Abbreviations pending

Association of Paediatric Anaesthetists of Great Britain and Ireland: http://www.apagbi.org.uk/
British Pain Society: http://www.britishpainsociety.org/pub_professional.htm
Paediatric Intensive Care Society: http://www.ukpics.org.uk/

MCRN/BSPED Diabetes, Endocrinology and Metabolic Medicine

British Society for Paediatric Endocrinology and Diabetes: http://www.bsped.org.uk
Diabetes UK: http://www.diabetes.org.uk/
Juvenile Diabetes Research Foundation (JDRF): http://www.jdrf.org.uk/

MCRN/UK Paediatric Gastroenterology, Hepatology and Nutrition

UC Ulcerative colitis
IC Indeterminate colitis
PCDAI Paediatric Crohn’s disease activity index
PUCAI Paediatric ulcerative colitis activity index
GOR Gastro-oesophageal reflux
GORD Gastro-oesophageal reflux disease
RAP Recurrent abdominal pain
IBS Irritable Bowel syndrome

British Association of Parenteral and Enteral Nutrition: http://www.bapen.org.uk
British Association of Parenteral and Enteral Nutrition: http://www.bapen.org.uk
British Association for the Study of Liver: http://www.basl.org.uk
British Liver trust (BTL): http://www.britishlivertrust.org.uk
British Society of Gastroenterology: http://www.bsg.org.uk
British Society of Paediatric Endoscopic Surgeons: http://www.bapes.org.uk
British Society of Paediatric Gastroenterology, Hepatology and Nutrition: http://bspghan.org.uk

Commonwealth Association of Paediatric Gastroenterology and Nutrition: http://www.capgan.org

European Society for Paediatric Gastroenterology, Hepatology and Nutrition: http://espghan.med.up.pt

**General Paediatrics**

XXX Abbreviations pending

Association of Paediatric Emergency Care Medicine: http://www.apem.me.uk/

British Association of General Paediatrics: http://www.bagp.org.uk/

British Society for Paediatric Dermatology: http://www.bspd.org/

**Methodology**

XXX Abbreviations pending

Website details pending

**MCRN/AMR Neonatal**

XXX Abbreviations pending

Action Medical Research: http://www.action.org.uk

BLISS: http://www.bliss.org.uk

British Association of Perinatal Medicine: http://www.bapm.org


MCRN Extended Neonatal Network: https://www.npeu.ox.ac.uk/neonatalnetwork

**MCRN/UK LSD Inherited Metabolic Disorders**

XXX Abbreviations pending

British Inherited Metabolic Disease Group: http://www.bimdg.org.uk
Gauchers Association: http://www.gaucher.org.uk

Neurosciences

British Association for Community Child Health (BACCH): http://www.bacch.org.uk
British Paediatric Neurology Association (BPNA): http://www.bpna.org.uk
British Paediatric Neurology Surveillance Unit (BPNSU): http://www.bpnsu.co.uk
European Paediatric Neurology Society (EPNS): http://www.epns.info
UK Children's Neurological Research Campaign (UKCNRC): http://www.ukcnrc.co.uk

Pharmacy and Pharmacology

Neonatal and Paediatric Pharmacists Group: http://www.nppg.scot.nhs.uk
Primary Care Pharmacists' Association: http://www.pcpa.org.uk
Royal Pharmaceutical Society: http://www.rpharms.com

Respiratory and Cystic Fibrosis

Asthma UK: http://www.asthma.org.uk
British Lung Foundation: http://www.lunguk.org
British Paediatric Orphan Lung Diseases: http://www.bpold.co.uk
British Paediatric respiratory Society: http://www.bprs.co.uk
European Respiratory Society: http://www.ersnet.org
National Paediatric Respiratory Nurses Group:
Appendix 4: Consumer Feedback Form

In order to improve our understanding of the impact that consumers have on research we would be grateful if you could use this form to record your feedback on the impact you feel you have on any of the meetings/projects/panels/groups that you contribute to in your role as a consumer involved in medicines for children research.

<table>
<thead>
<tr>
<th>Your name</th>
<th>Date of report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your email</td>
<td>Tel</td>
</tr>
</tbody>
</table>

Name of meeting/research/project/panel/group:

Name of person leading the meeting

Name of person leading research/project (if other)

Name of organisation leading the research/project

Meeting/session purpose

Your role at meeting/session
Please comment in the space below on the impact you feel that you have on the meeting/project/panel/group using the following points as prompts:

- Brief summary of your key points from the meeting/session
- Please describe how your participation contributed/influenced the meeting/session
- Please describe in what way you believe the meeting/session benefited from your participation
- How was your role and contribution perceived by other participants at the meeting/session?
- What aspects of your contribution to the meeting/session worked well/not so well? Please give explanations where possible.
- Please state proposed next steps/action points, if any, as part of your role
- Please comment on any further training/support needs for you or members of the group/team you are working with to enhance consumer involvement in medicines for children research

Please give examples to illustrate wherever possible.

Your comments:

Please email this completed form to Jennifer.newman@liverpool.ac.uk

Thank you for taking the time to complete this form. Please contact Jenny Newman MCRN Consumer Liaison Officer: 0151 282 4534 if you wish to discuss any aspect of this form further.

How this information will be used:
The information in this form will be used anonymously by the MCRN to inform annual reporting on consumer involvement as well as identifying future training needs.
NIHR MEDICINES FOR CHILDREN RESEARCH NETWORK

TOOLKIT FOR CONSUMERS

For more information, please contact:

Jennifer Newman
Consumer Liaison Officer
Medicines for Children Research Network
Institute of Child Health
Alder Hey Children's NHS Foundation Trust
Eaton Road
L12 2AP
Tel: 0151 282 4534
e-mail: jennifer.newman@liv.ac.uk

Developed by Joanna Worsfold, Sharon Douglas, Katharine Venter and Joanne Koukis (Consumer Representatives on the MCRN/Arthritis Research UK Paediatric Rheumatology CSG), in conjunction with Jennifer Newman, (MCRN Consumer Liaison Officer), with close collaboration with the Consumer Representatives from each of the other MCRN CSGs.