When a child commences treatment within the rheumatological services, the desire is to obtain the most effective, safe treatment available, based on evidence and tailored to the child’s needs. However, in practice, because of uncertainties about prognosis and outcome predictions for each child, it is often hard to determine what is the best treatment and for how long it will be needed, whether it will work and whether it will be safe.

Communicating the lack of robust evidence to support clinical decision-making is potentially difficult and may cause anxiety for families. However, it is important that families know about and understand this paucity of data and therefore that research is important and necessary in order to improve the evidence base. Such understanding is likely to improve recruitment to research studies, including clinical trials.

A recent report by the Royal College of Paediatric and Child Health [1] details the importance of paediatric research and the requirement of a shift in culture surrounding research in children. The National Institute for Health Research Medicines for Children Research Network (NIHR MRCN)/Arthritis Research UK Paediatric Rheumatology Clinical Studies Group (CSG) strategy incorporates the aim that all children treated within rheumatology should have the right to participate in a clinical trial [2]. Although there are examples of supportive and collaborative efforts for underpinning research, many difficulties remain in the recruitment to and retention in clinical trials. The consequence of this is that some trials fall behind projected recruitment targets, and either fail or lead to major delays in determining outcome and potential impact and improvement in patient care. So what are the barriers among families to taking part in research and how can these be overcome?

A recent NIHR MCRN consumer-led research meeting for charities and organizations supporting care and research within the field of paediatric musculoskeletal disorders asked representatives to identify the key barriers to participating in clinical research. The key obstacles were identified as a lack of information and awareness about research, a lack of enough time to ask detailed questions about research and perceptions that clinicians are too busy to explain research in detail, a lack of access to or awareness of on-going trials, fear of the unknown (e.g. the long-term safety of biologics), uncertainty about the impact of the trial, the potential demands on the child’s schooling, patient fatigue and time pressures on the family.

To overcome these barriers, doctors can change the timing of the introduction of discussions about research. At the time of diagnosis, families have an overwhelming amount of information to absorb and their immediate concerns may hinder any discussion about research. Families often focus on coping with the impact of the diagnosis, so this may not be the best time to raise the subject of research participation.

Online research could be promoted. Many parents go online to gather information about their child’s illness. However, a simple review of search engines and relevant websites found that using the search words arthritis, child and treatment rarely, if ever, readily returned research information on relevant charities, professional bodies or other educational organizations. If websites highlighted research, this would help to raise its profile and the awareness of its importance, significantly empowering parents to be more likely to ask questions about research at the clinic.

In order to attain successful recruitment and retention to studies, the study/trial design should be as pragmatic and real world as possible and demands kept to a minimum for patients, their families and clinicians.

Consumers should be engaged and involved in research. A key step for embedding research in clinical practice is to raise awareness through the ready availability or posting of information at clinics about opportunities for involvement in research and participation in studies. Discussions about research should be integral to every treatment conversation.

The NIHR MCRN [3] has actively supported the involvement of children, young people, parents and caregivers in all stages of the research process. Within the paediatric rheumatology community, research is prioritized and supported by the NIHR MRCN/Arthritis Research UK Paediatric Rheumatology CSG and a patient perspective is provided by four consumer members. The James Lind Alliance [4] and INVOLVE [5] are organizations whose aims are to ensure meaningful patient/public involvement and they have produced extensive literature and reports regarding this subject.

A positive message on the importance and value of research needs to be at the forefront of rheumatology services. Patients and families need to be aware of research opportunities and be helped to recognize that research addresses the need for robust, evidence-based answers to concerns about ensuring children receive the best treatments. Health care professionals need time and
encouragement to communicate the value of research and to highlight the current paucity of existing evidence in a supportive way without generating anxiety. A challenge for the rheumatology community is to define the training needs required to achieve this in the context of a busy clinic. If the importance of research is explained and it becomes integral to every treatment conversation, families may become engaged and involved partners and research can become more embedded into paediatric rheumatology.

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Sharon L. Douglas

1NIHR MCRN/Arthritis Research UK Paediatric Rheumatology Clinical Studies Group, Department of Women’s and Children’s Health, Institute of Translational Medicine (Child Health), Alder Hey Children’s NHS Foundation Trust Hospital, Liverpool, UK.

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Correspondence to: NIHR Medicines for Children Research Network Coordinating Centre, Department of Women’s and Children’s Health, Institute of Translational Medicine (Child Health), Alder Hey Children’s NHS Foundation Trust Hospital, Eaton Road, Liverpool L12 2AP, UK. E-mail: sdouglas@aberlady.org

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