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## **Example 5: National Institute for Health Research (NIHR) Clinical Research Network Children Specialty Rheumatology Clinical Studies Group**

**Using Facebook to ask parents and families about their priorities for research**

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### **About the Clinical Studies Group**

The [NIHR Clinical Research Network Children Specialty Rheumatology Clinical Studies Group](#) (CSG) provides free expert advice to help researchers develop high quality research proposals.

### **How have people been involved?**

There are three consumer members of the CSG. Sharon Douglas's daughter has juvenile arthritis. This led Sharon to co-found the [Scottish Network for Arthritis in Children](#) (SNAC), where she is currently a trustee. Sharon is also a member of the CSG; she joined as a consumer representative in 2008. Her current role on the CSG is as 'Consumer Champion', which means she supports other consumers who sit on the CSG.

Several years ago the CSG consumers wanted to know more about parents' priorities for research. Sharon and her colleague, Katherine Venter, tried to access parents' and families' views by approaching a number of arthritis charities, but got very little response. They were keen to reach parents and families they hadn't managed to reach through the charities. So they decided to post questions on two Facebook groups that are used by parents and families of children with juvenile idiopathic arthritis in the UK. These groups currently have over 1,000 members between them and are seen as a lifeline by the parents and families who use them. Researchers cannot join the groups, but they can ask to access them.

Sharon was a member of one of the Facebook groups so was able to put up a post herself. She had a good relationship with the administrator of the other group who endorsed the post. The post asked: "What are your top three concerns about your child's condition and care?"

### **What were the challenges?**

There were very few challenges. People need to know you and trust you before you can ask questions about your child's condition and care, so the fact that Sharon was a parent was important – it meant that the question was posted by a parent to other parents and families, so it didn't feel challenging in any way.

## **What resources were involved?**

There were almost no resources involved. Using Facebook was quick, easy and also more effective than using emails as you can see all of the discussion.

## **The impact of using social media**

Sharon received 40 replies from Facebook. Facebook groups have grown hugely in the last two years, and are now an important tool to support and connect families.

In total the CSG consumers received 200 replies, which identified 600 concerns. These mainly related to uncertainty about the progress of the disease and the side effects of treatments. The responses gave Sharon and Katherine the confidence to know that they were advocating for research that was important to parents and families.

Social media, and particularly Facebook, has also enabled parents and families to discuss research that is taking place. This wasn't possible previously.

## **The future**

Sharon and SNAC are now using Twitter and Facebook to facilitate discussions about research with parents and families (and researchers). They are also using social media to provide information surrounding access to studies, and to inform people about results of research.

## **Advice to other researchers about using social media to actively involve people in research**

“Social media should be viewed as an additional tool to involve the patient and public in all aspects of research.

“Social media is an easy way to connect with people. Start by finding charities that are relevant and build a relationship of trust. Involve them from the start – at the ideas stage.

“Be clear why you want to use social media as part of your research – is it to involve people, to recruit them or to disseminate results? Social media can enable you to link with people more closely and to get better answers to your questions.

“Social media can inform and engage people in research if it's done well - and people need to be aware of research before they can get involved.”

Sharon Douglas, SNAC Trustee, NIHR CSG Consumer Champion

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**Reference:** INVOLVE (2014) Examples of the use of social media for active public involvement - National Institute for Health Research (NIHR) Clinical Research Network Children Specialty Rheumatology Clinical Studies Group: Using Facebook to ask parents and families about their priorities for research