

# The role of social media in gathering data; an example from parents of children with Juvenile Idiopathic Arthritis (JIA)



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## Summary

Based on consumer led research with parents of children with JIA we found that a variety of methods are needed to obtain a wide collective voice.

## What we did

We sent a single item questionnaire to three charities, a research database and posted the question on Facebook.

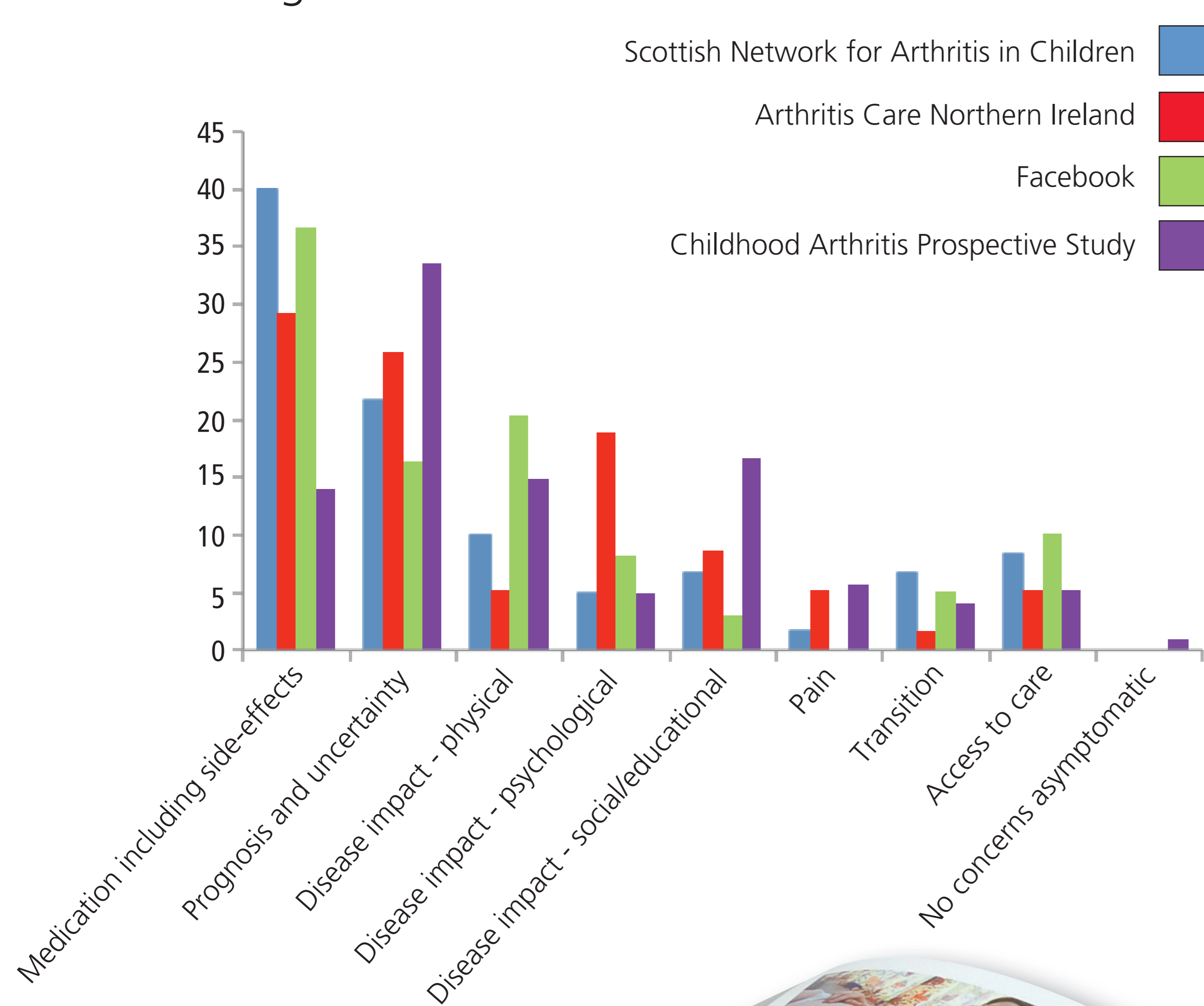
Respondents were asked:

“What are your top three concerns about your child’s condition and care?”

Of all the responses, Facebook was most rapid and most easily accessible.

## What we found

200 responses listing 600 concerns from which eight themes emerged:



## Parents’ concerns

- Parents’ main fears and worries were around the disease itself and the safety and efficacy of treatments
- By accessing a broader range of families we were also able to identify other concerns that may be less well understood
- **All these concerns can be seen under the umbrella of parents just wanting their child to have a normal childhood**

## Role of social media

- Social media has removed the isolation of the past
- It has created a community of families with similar situations
- Social media gives consumers a tool to be connected
- Parents talk about their child’s condition and treatment
- They **also** talk about research



The online community via social media is growing all the time e.g. the following JIA UK Facebook groups

- [www.facebook.com/groups/JAParentsFamiliesUK/](http://www.facebook.com/groups/JAParentsFamiliesUK/)  
**848 members**
- [www.facebook.com/groups/snacgroup/](http://www.facebook.com/groups/snacgroup/)  
**264 members**

## Conclusion

Social media is where Parents and families are talking. Our point is you can involve individuals in research, but if you want to involve a community in research, social media is where this community exists.

Social media is easy, cheap and accessible for researchers and convenient for families and therefore is an additional resource that should be drawn on.

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