

1st NEWSLETTER

We would like to start this newsletter by saying a huge

Thank you!

to everyone who has supported this study and given up their time to be in a focus group or attended our workshop, we couldn't do this important work without you.

Where did we start : this study is about improving support for families affected by a paediatric rheumatological diagnosis so this, we first wanted to talk to children, young people and parents/carers about your experiences.

An amazing.....

91

of you gave up your time to join a focus group!

Our focus groups included :

16 different paediatric rheumatology conditions

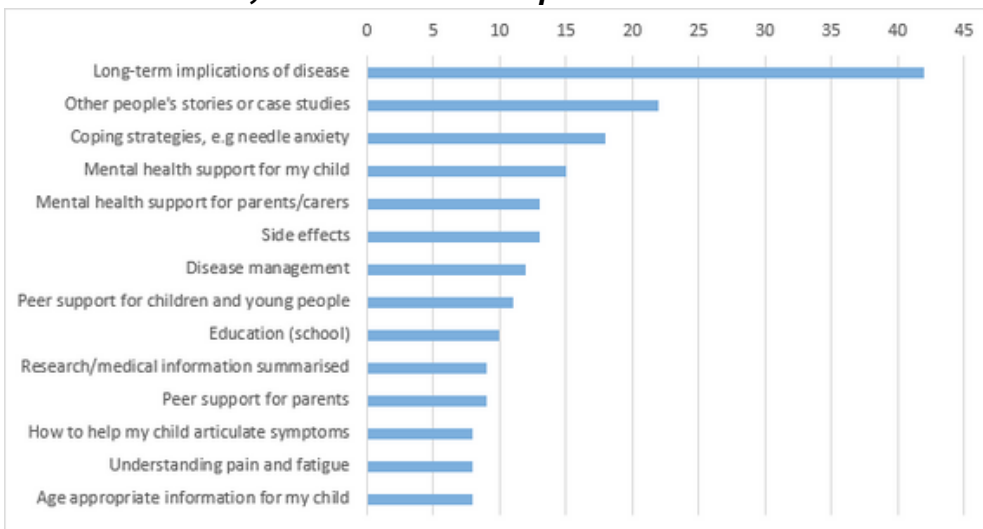
20 children between 8 - 17 years of age

6 young adults (21-29 year olds) who were diagnosed as children

65 parents (51 mothers and 14 fathers)

And an extra 70 health professionals from all over the UK!

Parents voted about what they would like more support with, these are their top answers:



Our focus groups ran from 19th Dec '23 to 9th April '24. We were blown away by the number of families reaching out through our website to offer to share their views. We spoke to nearly 4 times as many people as we originally set out to speak to!

We are still working through all the data, but so far we know families want....

Better communication

Better information

Empathy from health professionals

You also told us about the value of meeting others in similar situations!

We would now like to virtually speak to siblings in fun focus groups or individual interviews over the summer to understand their experiences and ideas, please email us if you have a child (8yrs +) interested : IMPACT_Study@gosh.nhs.uk

We also had our workshop in London on the 11th May '24 20 families moved around 8 'activity stations' to offer their ideas and give us feedback on the technology designs so far. It was a FABULOUS, fun day.



Thank you to everyone who attended!

