Exploring the experience of parents and carers of children with appearance affecting conditions or injuries

Online survey results summary

We greatly appreciate the time taken by all the participants to share their experiences. In total, 233 parents and carers completed the online survey. The questions within the survey were informed by parents and health professionals during previous in-depth interviews and focus groups.

Here is a summary of the results. Parents/carers who:

1. were more able to be kind and caring towards themselves during difficult times were less likely to experience difficult emotions, such as anxiety or stress.

2. felt more comfortable communicating about their child's condition or injury, both to others and to their child, were less likely to experience difficult emotions in their parenting role.

3. reported that teasing had a negative impact on their family were more likely to experience difficult emotions. Parents/carers also reported worries about teasing or other social challenges in the future.

4. felt more knowledgeable about their child's condition or injury and were satisfied with their treatment, were less likely to experience difficult emotions in their role as a parent/carer.

Overall, those who felt more confident in their ability to support their child to manage their condition or injury were more likely to experience positive emotions in their role as a parent.

What's next?

These results have given us a better understanding parents and carers' experiences of parenting children with appearance affecting conditions and injuries.

Using what we have learnt, the research team will now begin to design and develop new support materials for parents and carers. This will be done alongside a group of parent advisors to gain their advice and guidance on what kind of support would be beneficial.

Thank you again to everyone who took part in this study. This work could not be done without you and we are very grateful for your input.

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