

Rare Diseases Website Developing the Parent-to Parent content of a Rare Disease Website in Ireland (RD-WEB P2PS)

In 2014 parents participated in a previous study examining the development for the first Irish website for parents of children with rare conditions. A compelling finding from that study was parents' need for a live parent-to-parent support feature to be included in the proposed development of any website. Building on this, this study that was funded by the Irish Research Council and in collaboration with the Saoirse Foundation, investigated with parents' the idea of a live parent-to-parent support feature. The two studies are timely and coincide with the National Rare Disease Plan (DoH 2014) and the establishment of the National Rare Diseases Office (2015).

Aim

This study aimed to further explore parents' requirements for a live parent-to-parent support feature on the website.

Method

Ten parents were interviewed in the study.

Results

All participants had engaged previously with parent-to-parent support and online support communities. Parents strongly supported the development of an innovative Irish website for parents of children with rare conditions with a live parent-to-parent feature. Parents felt that living in Ireland they need the support of an Irish community to share experiences similar to their own. In the website content participants would like descriptions of conditions as they develop over the lifespan of the child, also information on undiagnosed conditions including those that are unexplained, a database containing parent details (similar to UNIQUE) and a system for parents to contact 'expert groups' of parents. They also indicated that while a website was very important it was not sufficient to meet their needs participants' required face-to-face meetings with other parents. Finally, parents felt that while this live site should have international links, it should be Irish, specifically supporting parents in Ireland and providing Irish information.

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