

# Developing Rare Resources for Scotland: Utilising methods of co-production to meet the needs of people living with a rare, genetic or undiagnosed condition and the health professionals involved in their care

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<sup>1</sup>Genetic Alliance UK is an alliance of over 200 patient organisations and the national charity working to improve the lives of patients and families affected by genetic conditions

## Background

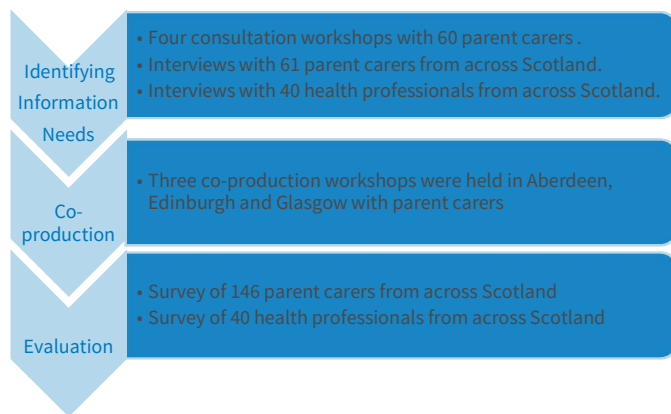
Reliable sources of information are essential for families living with a child or young person with a rare, genetic or undiagnosed condition, helping them to make informed choices about their care and to access support for their health and emotional needs. Families often report that they do not feel that they are given enough information at the time of their child or young person's diagnosis (Rare Disease UK, 2019).

## Aim

To identify and understand the information needs of families living with a child or young person with a rare, genetic or undiagnosed condition in Scotland and to produce a comprehensive information toolkit that could be provided to families as a source of information at the time of diagnosis.

## Method

Qualitative data was captured from 121 parent carers in Scotland and 40 healthcare professionals.



## Key Findings – Consultation Workshops and Interviews

- Participants were not satisfied with the information that they had received pre-diagnosis, at the time of diagnosis, and post-diagnosis.
- Participants value condition specific information, but recognise that there are limitations to the information available for rare conditions.
- Participants value health professionals that are honest about the limitations of their knowledge and support parent carers to source reliable information.
- Parent carers value signposting to sources of peer support and information on non-condition specific issues such as managing relationships and employment support.
- Health professionals often struggle to find accessible information on rare conditions that can be shared with families.



## Co-producing the Rare Resources Toolkit

Three co-production workshops were held with parent carers. Each workshop comprised three activities designed to shape the content and design of the Rare Resources Toolkit.

Activity	Description
20 Questions	Participants were tasked with compiling questions they had at the time of diagnosis. The top 20 questions were identified and were used to inform the content of the Rare Resources Toolkit.
Evaluating Existing Resources	Participants were given a selection of information materials to review. This activity was designed to identify what makes good quality information.
Top Tips	Participants were asked to consider what advice they would give to other parent carers and health professionals. The 'top tips' were included in the toolkit.

## Rare Resources Toolkit

The Rare Resources Toolkit was published in March 2019 and comprises seven downloadable sections:



## Evaluating Rare Resources

146 parent carers and 40 health professionals were sent an electronic version of the Rare Resources Toolkit to review and an evaluation survey to complete. The findings were overwhelmingly positive:

- 100% of respondents reported improved knowledge of the advice, support and services available to them.
- 96% of parent carers felt better able to support their child.
- 100% of health professionals reported feeling more confident supporting patients with a rare, genetic or undiagnosed condition

## Building Rare Networks with Rare Resources

The Rare Resources Toolkit will be distributed and promoted throughout Scotland in 2020. A programme of Rare Resources events will take place in Aberdeen, Dundee, Edinburgh, Glasgow and the Highlands and will seek to establish local rare disease information and support networks.