

10 simple steps to develop understandable condition-specific information

1. Check if a similar charity/support group exists (perhaps in the US, Canada or Australia) and has already published a guide or similar information online

If so, check if the organisation has a good reputation and if people living with the condition, carers and health professionals gave their views when developed. You may be able to review and tailor their guide with input from people living with the condition, carers and health professionals in the UK.

2. Gather the information that you would like to include in the guide

There are three options, depending on how much time and expertise you have:

- Use an international guide from an organisation with a good reputation if you have found one, and tailor the information for the UK.
- Start with what you know using your lived experience of being affected by the condition or caring for someone affected by it.
- Review published information using PubMed (pubmed.ncbi.nlm.nih.gov) or GeneReviews® (pubmed.ncbi.nlm.nih.gov/20301295/). DECIPHER (deciphergenomics.org/browser) can be helpful for conditions involving developmental delay and intellectual disability but it is more difficult to use.

3. Identify the most important information to share with a newly diagnosed individual or their family

The 'how to' guide template can be used to help you.

4. Writing your guide / leaflet

- Use a program that can be easily shared and edited by others, such as Word.
- Use a standard font available to everyone, preferably sans serif, such as Arial.
- Make sure the text has suitable emotional tone and is accurate and realistic.

- Make sure text is written in clear and simple terms. Remember the average reading age in the UK is 9-11 years.
- Use plain English and include medical terms or jargon afterwards. You can use the glossary in this toolkit to help.
- Signpost readers to support including 'genetic-change-specific' support groups (UK and globally) and other relevant charities.
- Ensure any website links are up-to-date, valid and 'clickable'.

5. Identify and contact suitable professionals to review your draft guide (preferably at least two professionals)

This could be a healthcare professional involved with a condition-specific clinic, someone from your local genetics team, a professional involved with the care of someone living with the condition, someone who has spoken about the relevant condition at a medical or research conference, or the first or correspondence authors of a GeneReviews® or relevant research study.

6. Send your draft guide for professional review then edit accordingly

You need input from professionals to ensure the guide is evidence-based and clinically accurate. Be clear with them what you are asking and give them a reasonable deadline. Explain that you are creating a guide for a public audience. You may need to simplify medical jargon that has been added by professionals.

7. Identify and contact suitable people living with the condition, or a family member of a person living with the condition, to give feedback on your draft guide (preferably at least two people)

You may want to pick one person with long-term experience of living with or caring for someone with the condition (who can provide expert input on what it is like to live with the condition), and one person who has or cares for someone with a relatively new diagnosis (who can flag up if there is information or language that they don't understand yet, and let you know if the tone feels friendly and supportive for someone new to the condition).

8. Send the draft guide for lay review by individuals and family members then edit accordingly

You need input from individuals and family members to make sure the content reflects people's lived experience of the condition, the content is clear and easy to understand, and the tone is supportive and friendly. Be clear with them what you are asking and give them a reasonable deadline. You may also want to ask them for personal quotes and/or photographs to include in the guide. If you do, you will need their written signed consent to use their quotes and photographs in the guide.

9. Make changes to take on board the feedback from your reviewers, proof your final version, and save it in an appropriate format

You need to take on board the feedback from reviewers. If they give conflicting or complicated feedback on a particular section, then you may want to re-draft it and check the updated text with them. Once you are happy with a final version, share it with someone who hasn't seen it before (this can be a friend, family member or colleague) and ask them to read it and spot any spelling or grammar mistakes. You can use the 'how to' guide on formats to help you decide which formats you want to use to save the final version so it is as accessible as possible.

10. Upload the guide to your website (if available), promote and share on various social media platforms

You can send a copy to everyone who contributed and individuals and families affected by this condition. Remember not everyone uses the internet and some people may prefer a printed version in the post. You may find that including a copy in a regular mailing or a link in an article in a regular electronic newsletter is a simple and affordable way to reach people. You may also want to contact NHS clinicians and clinics to see if they want a link to share with newly diagnosed families.