

Creating information about genetic and rare conditions that is easy to understand

These guidelines will help you to create information that is accessible and easy to understand. You don't need to achieve everything listed here. The most important thing is to follow the relevant guidance and produce information that is simple, understandable and created with your audiences in mind.

Key points

- All information you create should be written in plain English with a target reading age of 9-11 years, which is the average level of literacy in the UK. This will make sure it can be understood by as many people as possible. This document is a good example.
- Your content, and how it is presented and shared, should be tailored according to the condition it relates to and the people likely to be accessing it.
- Consider people with vision and hearing impairments, motor difficulties, cognitive challenges, learning disabilities and/or if the condition disproportionately affects a community where English is not their first language.
- Put yourself in the shoes of the likely audience, anticipate their accessibility requirements and provide easy ways for them to request alternative formats.
- Never assume that any of your readers have expert knowledge of their condition. Even if someone has had a condition for a long time, they may experience new symptoms, find out about new treatments, or have received their diagnosis a long time ago. All these factors affect their understanding and ability to access care.

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Written information - getting started

- Know who you are writing your information for, and keep them in mind. You can be clear about this with your audience, for example with an introduction that says “This information sheet is for...”
- If you are writing information for children and young people, people with cognitive impairments or learning disabilities, or people with a very complex condition, you could consider having a separate ‘easy read’ version. There is more information about easy read versions later in this guide.
- Take a clear and straightforward approach to creating information so that you create accessible content the first time, every time.
- Simplify your content and only include the main points that people need to know. You can include information on how to find additional knowledge and support.
- Create your information using a common computer program, for example, Microsoft Word or PowerPoint. This will make it easier to send, open and print your information. Information saved as a PDF

file can't be easily edited and may not work well for people who use assistive technology.

- Use a simple font like Arial, Helvetica, Tahoma, Verdana, Calibri, Segoe or Gill Sans at a minimum size of 14 points and ideally at large print size of 16 points. Avoid using italics, all caps text and underlining (except for links).
- Make sure your information asks people if they have any communication needs or need to be given information in a certain way.
- Provide a variety of ways for people to contact you, for example:
 - email address
 - telephone number
 - text message
 - website
- Give the information a meaningful and clear title so that it is understood from the start.

Format and layout

- **Break up your text to make it more readable.** Use bullet points, numbered steps and section headings.
- **Avoid space saving devices such as brackets and 'and/or' where possible as they make things more difficult to read.** Try and also avoid using contractions such as 'it's', 'can't', 'don't', 'won't', 'shouldn't' as these are more difficult for screenreaders. They are also harder to understand for people who do not have English as a first language.
- **Use clear and simple language.** Most people, including specialist audiences, prefer simple language. This is particularly the case when you are communicating medical or scientific information which is already challenging for lay people to understand. You can use the glossary that is part of this toolkit to help.

- **Keep sentences and paragraphs short.** Try and stick to one idea per sentence. Aim for less than 25 words per sentence. It may be helpful to read your information out loud back to yourself. This will help you to spot if a sentence is too long to read in one go, or any words are too long and complicated.
- **Avoid using too many medical terms, abbreviations or acronyms, and if you need to use one then explain what it means the first time you use it.** Always try to put the plain language in first, then add in the medical term afterwards. You could say “xx this is sometimes called xx”. You can use the glossary that is part of this toolkit to help you when writing your document, consider putting in a short glossary at the end of your document to list and explain any terms you have used.
- **Consider adding extra space between the lines of your text as this will make it easier to read.** For example, in Microsoft Word choose 1.5 line spacing instead of single line spacing.
- **Do not try to squash things in or fit too much information on one page.** Do not split words over lines or sentences and paragraphs over pages. Lots of white space makes the page look less intimidating and helps people find their way around your information more easily.
- **If you are printing your information, use matt paper rather than shiny paper.** This will make it easier to use with assistive equipment and technology.
- **Headings give your document a structure and help people navigate it.** This helps all people but is especially important to those using screen readers. The heading styles in computer programs like Microsoft Word are not for decorative effect, they actually apply to the structure of the page so use the right heading style at the right time, not the one you think looks best. Apply heading styles to your text by highlighting it and selecting a heading style from the list that can be accessed via the ribbon at the top of your screen when using Word, Powerpoint, GoogleDocs, etc. For help with this, search online for ‘improve accessibility with heading styles.’

Numbers and symbols

- All numbers should be expressed as simply as possible with a target numeracy age of 9-11 years, which is the average level of numeracy in the UK.
- **Express all numbers in figures, including 1 to 10.** However, for millions, write 3 million, 20 million.
- **If possible, use ‘half’, ‘a quarter’ or ‘1 in 5’ rather than percentages.** When referring to percentages, say 67 out of 100 or 67 per cent (rather than the symbol %). Use whole numbers (7 per cent is better than 6.8 per cent), unless the sense demands greater accuracy.
- **It can be useful to provide visual representations or descriptions of what you mean.** For example: ‘This condition affects an estimated 1 in 10,000 births. To put this into perspective: Wembley Stadium has a capacity of 90,000 – around 9 out of 90,000 people in a full stadium would have the condition.’

Colour and images

- **Be aware that some people reading your document might be colour blind. When designing your information don’t rely on colours alone to make things clear.** If your intended audience may have vision impairment, consider using colour contrast so that your information is easier to read (for example, black text on yellow background).
- **Don’t use images for the sake of it. If an image or photo doesn’t help to explain the text then don’t use one.** When using images or charts, consider making the same point in text so that people with visual impairments can access the information.
- **Remember that people may be printing your information at home on an old printer.** Simple black-and-white text documents

are a lot cheaper and easier to print at home than a full-colour document with lots of photographs.

- **If you do use images and photographs, think about where they are needed.** For example, would an image help to illustrate a complicated medical point? If you are using photographs then consider using images that are representative of people with lived experience of the condition. Depending on who is affected by the condition, you may wish to include photographs of children, adults, people walking and/or using mobility aids or wheelchairs, a mix of men and women, and people with different skin tones. You need to check that you have written signed consent for any images or photographs that you use.
- **Use ‘alt text’.** Alt text is text that you add to describe the function or appearance of an image and it reads aloud if people are accessing your information using screen reader software.

Website links

- **When using links, make sure the link text clearly describes where the link goes.** It should be understandable on its own, even if it is read out of context.

Example of accessible link text

Further information can be found on the [Genetic Alliance UK website](#).

Example of less accessible link text

[Click here](#) for further information.

- **Use clear headings and subheadings.** This will help make your information more visible if people are using a search engine such as Google to find information.

Written information – top tips

Remember that it is not about how much information you give to people. What matters is how much of it is understood. If you are worried that you are leaving too much information out of a document, provide accessible details of how people can find out more.

Accessibility is more important than the way your information looks. You might spend a lot of time and effort making a document look impressive and professional but if people can't understand what it says, then that effort is wasted.

Think about how you distribute your information. Put your information in places accessed by the people you want to read it.

Try and write in active rather than passive language as this is more engaging and easier to read e.g. 'Prescriptions are written by doctors' (active) rather than 'Doctors write prescriptions' (passive)

Try to include quotes from people who have lived experience of the condition. This helps people feel less isolated and can add personality and interest to break up the more complicated and clinical information. You need to check that you have written signed consent for any quotes that you use.

Written information – accessibility checklist

1. Is the information in a program or format (for example, Microsoft Word) that can be easily edited, sent via email, shared as a digital file and printed?
2. Does the information have meaningful titles and use clear and simple language?
3. Is the information presented in a simple font (for example, Arial) at a minimum size of 14 point?

4. Can the information be broken up with bullet points, numbered steps and subheadings?
5. Have any technical terms, abbreviations and acronyms been explained?
6. Can documents referred to in the information be found easily?
7. Do you have written signed consent for any photographs or quotes that you are using?
8. Do images have alt text? (Alt text is necessary if images will be viewed on a screen)
9. Is contact information provided?

Alternative formats

‘Easy read’ guides

Consider developing a separate ‘easy to read’ guide if your information is for specialist audiences, people with cognitive impairments or learning disabilities, or children or young people. Images and symbols can be very helpful in ‘easy read’ guides. There is further information at <https://pifonline.org.uk/resources/posters/easy-read-matters-poster/>.

If you are not familiar with ‘easy read’ versions, Macmillan are a good example of providing a comprehensive range of easy read medical information. [Easy read cancer information | Macmillan Cancer Support](#)

Large print and giant print

The size of a font is described in point size. Regular print is usually 12 point. Large print is generally 16 to 18 point size and giant print is anything larger than that. It is simple to adjust print size in programs like Microsoft Word and GoogleDocs which is why we recommend using them to create information.

Audio

It is easy to create information in audio format. Simple and free voice recorder apps are available for use on Apple or Android smartphones, tablets and computers, and most devices have in-built audio recording functionality. The audio recordings you create can then be shared as digital files via email and messaging and also added to your website.

Video

If you have a smartphone, tablet or computer then you can create information in video format. Most smartphones can record video and free apps are also available to download. These will record video and many will also add subtitles or closed captioning automatically (although this is not always accurate, particularly for clinical terms, so you will need to check it). The video content you create can then be shared as digital files and added to your website.

If any people appear in your video, ensure that they appear in the middle of the camera frame, and are in a well-lit space that does not have shadows.

Tips for creating audio and video content

- Try to find a quiet space to record with minimal background noise or interruptions.
- Ensure you're comfortable before you start recording and that the information you will be reading out loud is easy to see (making the text larger and increasing the spacing can help with this).
- You don't need to record everything in one take. All recording apps can be paused and most have basic editing capabilities so re-recording and fixes are possible.

- Slow down. Take your time and speak clearly.
- If possible, film in landscape mode (so that onscreen it's wider than it is high) rather than portrait mode. Landscape is a better format for viewing.

Tips for creating audio content

- Put your recording device (smartphone, tablet or computer) at the same height as your mouth. There are flexible clamp mounts you can attach to surfaces that grip devices in your preferred position. Alternatively you can put your device on a stable platform made from a stack of books or boxes.
- Hard surfaces in your recording space will create echo. If possible, record your audio while underneath a blanket or duvet. It will absorb noise and improve the overall sound quality of your audio recording.

Useful links for additional guidance on accessibility

Patient Information Forum

The Patient Information Forum (PIF) is the membership organisation and network for people working in health information and support. PIF provides training and resources to help make high quality health information more accessible, and also runs the only quality mark for health information in the UK - the PIF TICK. There is a membership fee to join PIF, together with an annual fee and assessment to become PIF TICK accredited.

pifonline.org.uk/resources/how-to-guides/

WAVE Web Accessibility Tester

Enter a webpage address and the evaluation tool will test accessibility and show where improvements can be made.

[WAVE Web Accessibility Evaluation Tool](#)

The Hemingway App

The Hemingway App is a helpful free website tool you can copy and paste text into that gives guidance on a reading age estimate and suggestions for improvements in readability:

<https://hemingwayapp.com/>

Royal National Institute of Blind People

www.rnib.org.uk/living-with-sight-loss/independent-living/accessible-nhs-and-social-care-information/creating-accessible-information-and-communication-resources-for-health-and-social-care/

Royal National Institute for Deaf People

rnid.org.uk/information-and-support/support-for-health-and-social-care-professionals/communication-tips-for-healthcare-professionals/

UK Government blog on accessibility

accessibility.blog.gov.uk/2016/09/02/dos-and-donts-on-designing-for-accessibility/

Easy Health library of accessible health information

<https://www.easyhealth.org.uk/>