

Findings from PIF survey (28/09/2021)

Introduction

The following document details the results of a survey carried out by NHS Digital in collaboration with the Patient Information Forum (PIF). The survey was shared with PIF members. The survey asks questions about the creation and sharing of accessible formats of information, such as translated or simplified materials.

Respondent information

As of Tuesday 28 September 2021, there were a total of 46 respondents.

Introduction questions

What type of organisation do you work for?

The majority of respondents are working in a charity (55%) or NHS local health trust (26%).

Others included:

- National NHS organisation (4%)
- Private sector (6%)
- Ex-pharmaceutical (2%)
- Government (2%)

Which of the following formats has your organisation provided health information in?

Most organisations had provided health information in Easy Read documents (24%) or paper resources written in other languages (14%). The least provided formats were audio in other languages (4%) and British Sign Language (4%).

Others included:

- Social media posts (14%)
- Digital resources written in other languages (13%)
- Easy Read animations or videos (8%)
- Videos in other languages (8%)

Charities were more likely to provide Easy Read documents, digital resources in other languages and social media posts. NHS local health trusts were more likely to provide Easy Read documents and paper resources in other languages.

Other formats that respondents mentioned included:

- Versions specifically for teenagers and young adults
- Large print
- Videos and audio in English for spoken word
- Braille
- Patient information leaflets in accessible formats

2 respondents had not provided health information in any of the formats asked about.

What are the reasons your organisation has not provided health information in any of these formats?

Those 2 respondents indicated that time and financial constraints were the reasons why they had not provided health information in any of the formats we asked about.

Thinking of the last time you created this information...

What format was it in?

Most organisations had created information in Easy Read (29%) and paper resources written in other languages (19%). The least created formats were British Sign Language (4%) and audio in other languages (4%).

Others included:

- Digital resources written in other languages (17%)
- Social media posts (14%)
- Videos in other languages (5%)

Charities produced most of their information in Easy Read, and digital and paper resources written in other languages. NHS local health trusts produced most of their information in paper resources written in other languages and Easy Read.

What information did you produce in different formats?

Most organisations created information about a condition (19%), and information about a procedure (18%).

Others included:

- Preventative healthcare information (14%)
- Long-term condition management information (14%)
- Information about medication (9%)

Other types of information respondents mentioned:

- Information about cancer
- A local directory of services
- How to do a COVID PCR test at home
- Awareness information
- General COVID information
- End of life and bereavement information

Charities were more likely to provide information about a condition, closely followed by information about a procedure, or long-term condition management information. NHS local health trusts were more likely to provide information about a condition and preventative healthcare information. Private sectors were more likely to provide information about medication.

What languages did you translate information into?

We did not receive any answers to this question. This may have been due to a survey routing error.

Who created the content?

Most organisations used their internal teams to create the content (42%).

Others included:

- External agencies (14%)
- Frontline staff (14%)
- Patients (12%)
- External teams, such as specialist charities or organisations (6%)

Other places respondents mentioned using included:

- External contacts who had the right language skills
- The adult learning disability team in the community
- Translators
- Pharmaceutical companies, that are approved by the regulatory body
- One used multiple areas, such as creating the content themselves, using a local charity to translate into different languages, and an external agency to do the Easy Read

Charities were more likely to use their own internal teams. NHS local health trusts relied more on frontline staff, such as doctors or nurses to create content.

What support did you receive to create this content?

37% of organisations had a budget to create the information. 25% had dedicated time to do the work. 20% had a dedicated internal team, and 5% had a dedicated external team. Only 3% had training support to create content.

Respondents also talked about having no support at all, and having to juggle other projects whilst doing this work.

Charities were more likely to have a dedicated budget and team to do the work.

How did you decide to work on this project rather than other projects?

Most organisations decided to create this information due to requests or demand from certain audiences, or professional bodies. Others had identified that the information required was a priority. Some said that it's just their job to provide this content, it's part of what they do on a regular basis. Some others mentioned that creating this content was done alongside other projects, it was not the only thing they were expected to work on.

- Respond to requests / demand (from users or organisation) 7
- Identified a priority by organisation 4
- "It's our job" 3
- Juggling with other projects 2
- They were offered support 1
- Up and coming format (social media) 1

How did patients access the information you produced?

Information could mainly be accessed via a website (25%). This was closely followed by the hospital (10%), and the post (10%). The least used methods of access were Instagram and YouTube (3% each), and community centres (2%).

Others included:

- Facebook (9%)
- Twitter (9%)
- Support groups (8%)
- Email (6%)
- GP practice (4%)

No one indicated using WhatsApp, text message, Snapchat, or TikTok.

Charities mainly used a website to let people access information. NHS local trusts were more likely to use post, closely followed by websites.

Other methods mentioned:

- Face-to-face
- LinkedIn
- Telephone support line or helplines
- Dedicated care centres
- Walk-in centre
- Digital signage in hospitals
- Medical devices (instructions for use)
- Patient information leaflets
- Audio on a CD

How did you involve users in creating the content?

The most common way to involve users in creating content was to get them to review content after it was created (28%).

Others said they:

- Created the content together with users (17%)
- Did user testing at the development stage (15%)
- Did interviews or focus groups (11%)
- Completed an impact assessment following launch (6%)

13% of respondents said that they did not involve users in creating the content.

Other respondents mentioned that they were not aware of the user involvement as the process was led by an external organisation. One said that the information was needed very quickly, so they translated existing information and did not go through with usual user testing on the translated information.

How did you involve users in sharing the content?

The most common way to involve users in sharing content was to use community contacts to share information and ask users to share on social media (both 25%). This was followed by providing physical materials to be handed out (20%).

20% of respondents said they did not involve users in sharing the content.

Others talked about using social media and other media channels, but not explicitly asking users to share the information. One mentioned having a highly ranked website on Google, which gave them very high levels of traffic.

How often do you review and update accessible formats?

The majority of respondents said they review and update more than every 2 years (41%).

Charities and NHS local health trusts were less likely to regularly update their information, with most of them saying they review and update at least every 2 years. Private sector organisations were more likely to regularly update, saying they would update every week or every 6 months at least.

Do you have a specific budget to review and update accessible formats?

Most respondents said they do not have a specific budget (42%). Quite a large proportion were not sure if they had a specific budget to review and update accessible formats (26%). Out of the 30% that said they did have a budget, half had a budget they controlled and half had a budget they did not control.

What three things went well with this work?

The majority of respondents mentioned the positivity of sharing and hearing back from patients and people. Having feedback on what worked for them was good, and they were able to increase awareness of things that mattered.

Others mentioned that doing this work enabled them to increase their reach and be more inclusive when providing information for patients. Some felt that the way they worked with translators was really positive, and the process allowed them to optimise their delivery of information. For others, it was great to be able to create with other teams, and with the users of services.

Reach and inclusion

- Reach of social media
- Reach audiences that other forms of information provision have missed
- The inclusion of patients and users in the work
- Extensive user testing
- Filled an identified gap
- Involved target audience in production
- Able to see reach of more people
- Understanding users and their community needs

Sharing and hearing back from patients / people

- A quick and easy way to share information
- Feedback
- Good feedback from patients
- Increase awareness of need for accessible information to be made available for patients
- Successfully raised awareness of cancer registration and its benefits (Less opt-out requests)

- Collaboration with hospital trusts (although we could extend beyond to support groups etc)
- Able to track usage
- Information about screening in Welsh
- Easy read content on good bowel health
- Consistency of the type of information

Optimisation of Delivery

- Speed of delivery from concept to going live
- Development process
- Focus group implementation

Creating with others

- Working with internal teams to create, publish and share
- Co-creation
- Client satisfaction
- Supportive of the work

Using translation and services

- Translators were very effective
- Solid health communication at the end
- Speed of translations
- Assists our helpline with both readers and professionals
- Translation service
- Quick turn around
- Accessible
- Able to share documents quickly
- Organizational support

What three things would you do differently if you were to do this work again?

People focused on wanting more time to do the work, to be able to do it properly. There was also a want to be able to involve more of the community and healthcare professionals in the process, especially when assuring the quality of translations. People were also looking to explore more formats and expand production, as well as have better budget allocation to do all of the above!

A small proportion were happy with their process, but potentially wanted to be able to do more.

Project Timeline

- Start the process earlier
- Allow more time
- Create more deadlines
- Better launch
- Dedicated time to this work
- Allocate enough lead time to develop
- Plan a workstream
- Would have liked to have produced it faster but workload was too busy at the time

Community involvement in quality

- Involve specialist organisation in planning stage - support with aims
- Include someone who would use the information production process
- Quality control
- More pre-planning (less reactive creation)
- Ask a native speaker to check translation
- Find reviewers in advance and speak to them face-to-face or over the phone to make sure they understood we wanted conversational tone (translations can be correct but very formal)
- Ask for feedback when materials have been made accessible on request
- Go to a different agency for the easy read documents
- Involve users when creating Easy Read versions

Content distribution

- More formats (Definitely!)
- Print more materials
- Look at alternative types of media
- Would like to evaluate if it met people's needs / if other formats could meet their needs better (Audio)

Budget Allocation

- Have specific budget to make more people aware of the information
- Allocate dedicated budget resource as part of overall budget planning
- Have budget to maintain and review the resources
- Be Extra clear to the charity how much budget was available

Perfect system

- N/A We are happy with our system and would do more if we can, but work within the resource and budget we have
- Nothing - rest of process was simple and works well

Involving healthcare professionals

- Ability to involve healthcare professionals and understand the main barriers they face with people who have language barriers. How do those people access our information?
- Involve more clinicians