



Patient
Information
Forum



PIF Health and Digital Literacy Survey

Executive Summary

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Introduction

This report outlines the results of our 2022 survey and sets out progress made in the crucial areas of health and digital literacy since the pandemic.

The results are encouraging. PIF's last survey in 2019 found 13% of organisations had a health literacy strategy in place and just 50% assessed the equalities impact of digital projects.

By 2022, 33% had a health literacy strategy and 80% of respondents considered equalities impact of digital tools. In comparison, the period between 2013-2019 had shown very little progress.

However, worrying trends are revealed by the 2022 data.

A lack of resources is the major barrier to action on health and digital literacy for NHS organisations and charities.

Susceptibility to misinformation is now seen as a key challenge for people with lower health literacy.

Digital exclusion is preventing some people from accessing an increasingly digital NHS.

This report makes recommendations for action on health and digital literacy. We are encouraged that 75% of respondents have used PIF services to support expertise in this area. Our recommendations focus on what works and what needs to happen nationally.

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Executive summary

Health and digital literacy context

While the pandemic emphasised the links between low health literacy, digital literacy and health inequality¹, the need for health information people can understand and use extends to all health conditions.

This is particularly true of conditions linked to inequality. For example, obesity, chronic obstructive pulmonary disease (COPD), diabetes and cancer.

The Core20PLUS5 approach has highlighted the need for targeted, culturally appropriate information to tackle health inequalities.

However, lower levels of health literacy continue to limit people's ability to take part in shared-decision making, understand risk information and make informed decisions.

Research shows 43% of the working-age population struggles to understand health information².

Data from 2022 found only 32% of people understand the medicines package leaflet which details risks and benefits³.

1 in 10 people in the UK lack the digital skills to manage their health⁴. Even for those who do have skills, digital poverty is likely to be an increasing barrier⁵. And those who are offline reported the NHS as the most difficult service to interact with in 2022⁶.

Digital innovation is at the heart of NHS plans for recovery. Addressing health and digital literacy needs is critical to success.

By May 2022, more than a third of people had already reported that the rising cost of living was impacting their ability to go online⁷.

References

1. Public Health England, 2020. Beyond the data: Understanding the impact of Covid-19 on Black and Minority Ethnic Groups. Accessed September 2020: assets.publishing.service.gov.uk
2. Rowlands G, Protheroe J et al, 2015. BJGP, 65(635): e379-e386. bjgp.org/content/65/635/e379
3. Is it time to re-imagine product information for human medicines? Kent Surrey Sussex Academic Health Science Network, Unity Insights and the UK National Innovation Centre for Innovation for Ageing (Newcastle University), 2022
4. Essential Digital Skills UK 2022 ipsos.com/en-uk/essential-digital-skills-uk-2022
5. Good Things Foundation (2023), Health inequalities and mitigating risks of digital exclusion. goodthingsfoundation.org/insights/health-inequalities-and-mitigating-risks-of-digital-exclusion
6. Lloyds Bank Consumer Digital Index 2022 lloydsbank.com/assets/media/pdfs/banking_with_us/whats-happening/221103-lloyds-consumer-digital-index-2022-report.pdf
7. Essential Digital Skills UK 2022 ipsos.com/en-uk/essential-digital-skills-uk-2022

The 2022 survey

Our 2022 survey aimed to see what progress had been made since the pandemic and if health information producers had heeded our call to become health and digital literacy friendly.

Survey respondents

The survey ran October – December 2022.

- 111 responses
- Charities were the largest group of respondents (38%)
- Followed by NHS organisations (28%)
- 54% said their information was for the whole of the UK
- 37% of organisations have information teams of up to five people

67% said the pandemic prompted their organisation to give higher priority to health and digital literacy.

Respondents felt the biggest impact of low health literacy was problems communicating with healthcare professionals (85%). This was closely followed by being more vulnerable to misinformation and disinformation (83%).

Digital access as a 'vital sign'

Digital skills are now fundamental to a person's ability to access healthcare services and understand information.

71% of survey respondents felt the ability to access digital services should be a health 'vital sign' equivalent to being housebound. Support was highest in NHS organisations (85%).

Progress since 2019

The latest survey results show there is greater awareness of the vital importance of health and digital literacy.

In 2022, 80% of respondents said they considered equalities impact when implementing digital tools. This was real progress from 50% in 2019.

There was also progress in the number of organisations with a health literacy strategy – up to 33% from 13%.

Steps taken to improve health literacy included:

- Involving users in the production of health information (81%)
- Chunking information and providing key point summaries (63%)
- Aiming for a target reading age (62%)
- Using alternative formats (62%)
- Training staff (59%)
- Meeting the PIF TICK requirements (47%)

47%

of respondents
meet the requirements
of the PIF TICK quality mark
for health information

Trusted
Information
Creator



However, there is still work to be done. A lack of resources was identified by 72% of survey participants as the main barrier to producing health-literacy friendly information – up from 64% in 2019.

Respondents producing information for people with English as a second language fell to 44% from 57%. Up to 1 million people do not speak English well or at all¹.

Those providing information specifically for people with learning disabilities fell from 56% to 41%.

Levels of health literacy – the digital dimension

Functional: Having the basic skills needed to function in everyday life and typical healthcare interactions. For example, the ability to read appointment letters, follow simple medicine instructions or attend a virtual appointment.

Interactive: Ability to interpret and balance information from different sources as part of the decision-making process. Confidence and motivation to seek out information and make decisions. For example, using digital decision aids and finding trusted health information.

Critical: Ability to appraise information critically and make challenges. For example, the ability to use a Personal Health Record to request patient-initiated follow up or use a virtual ward.

WHO definitions

Health literacy

'The personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.'

Digital health literacy

'The ability to seek, understand and appraise health information from electronic sources and apply the knowledge gained to preventing, addressing or solving a health problem.'

What happens now?

Access to health-literacy friendly information and appropriate digital tools is a vital determinant of health.

To achieve the aims of shared decision making, self care and self management, we must ensure everyone has access to information they can understand and use.

This report updates our recommendations from 2020 and identifies new actions.

Together we can improve access to health information and support for all.

Reference

1. ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/english-language-skills/latest

Recommendations 2022

1. Health policy

Incorporate health and digital literacy into health strategies of the four nations as a key enabler of recovery. This will support shared decision making, self care, self management and reduce health inequality. The NHS should support development of 'health literacy friendly' organisations.

2. Health literacy friendly organisations

Organisations should aspire to become 'health and digital literacy friendly.' All organisations should implement the Accessible Information Standard.

3. Equalities impact of digital tools

All organisations should consider the equalities impact of digital tools. The inability to access digital services independently, safely and confidently should be a health 'vital sign'. The NHS should encourage digital health hubs and use free resources like the [Good Things Foundation's](#) National Databank and National Device Bank.

4. NICE

Ensure health and digital literacy is recognised in new and updated NICE guidelines, with particular reference to digital technologies.

5. Shared Decision Making

Campaign for the provision of 'health-literacy friendly' patient information that conforms to the [NICE Framework for Decision Support](#) tools. Change the regulatory framework for medicines information to make medicine package leaflets more accessible to patients.

6. PIF TICK

Expand the PIF TICK to ensure best practice in health and digital literacy is translated into action by information producers.

7. NHS England Content Standard

The standard should be mandatory for all NHS organisations in England. National NHS bodies should take a 'Do it once. Do it nationally' approach to information on key priorities to avoid duplication and promote consistency.

8. PIF Guidance

PIF to develop a guide on how to carry out health and digital literacy audits. Promote existing resources, knowledge and tools on health and digital literacy. Develop a health literacy checklist for information producers.

9. Translated health information

Create a central repository for information in commonly spoken languages to help reduce health inequality. Campaign for the NHS Apps and other national websites to be made available in commonly spoken languages.

10. Skills improvement

Support digital and media and information literacy skills improvement. Work in cross sector partnerships with the [Media and Information Literacy Alliance](#) to signpost credible health information in all formats to the public via social media, libraries, schools, prisons, pharmacies and community based support.

Key findings

Health literacy strategies

- 33% of organisations had a health literacy strategy in place in 2022 (up from 13% in 2019)
- 16% had health literacy embedded in a wider strategy
- 7% had a health literacy strategy in development
- Charities were most likely to have a health literacy strategy (38%) and NHS organisations least likely (18%).

Of respondents that had signed PIF's health and digital literacy charter 45% had a strategy in place, as did 37% of responding organisations accredited by PIF TICK. In both these groups another 4% had a strategy in development.

Impacts of low health literacy

- Problems communicating with healthcare professionals (85%)
- Being vulnerable to misinformation and disinformation (83%)
- Problems navigating the health and care system (79%)

67% said the pandemic prompted their organisation to give higher priority to health and digital literacy

Case study: Health literacy champions

Dorset County Hospital NHS Foundation Trust runs a health literacy champions scheme.

Library and Knowledge Specialist Morag Evans recruited members of staff from different departments.

The scheme includes:

- Champions meetings every two months
- Reports to the Health Inequalities Group
- Health literacy training for new doctors
- A health literacy bulletin

The scheme has informed marketing strategies, displays and other promotional material produced.

Staff have been encouraged to demystify and simplify terms. For example, developing and reviewing a set of health inequalities 'postcards', designed to break down the jargon involved in health literacy and inequalities.

Healthcare librarians from Dorset County Hospital and University Hospitals Dorset have delivered health literacy workshops to public librarians.

Evaluations are captured using Slido and used to inform and improve training.

Feedback has also been positive on an impact survey sent to staff who complete training.

Top Tip: Be patient – raising awareness and bringing about change takes time!

Barriers to producing health-literate information

- Lack of resources (72%)
 - up from 64% in 2019
- Limited understanding of how to develop health-literate resources (64%)
 - down from 73% in 2019
- Difficulties involving diverse users in information development (61%)

Lack of resources was a larger barrier in the charity sector (85%) and NHS (82%) than in the private sector.

In 2019, 64% of respondents identified lack of understanding of need as a barrier. This fell to 51% in 2022.

What national action on health literacy would support improvement?

1. Wider adoption of the PIF TICK to create a consistent standard (75%)
2. A national strategy for each of the four nations (73%)
3. NICE guidelines (65%)

Although NHS Trusts were less likely to have PIF TICK, 86% felt wider endorsement would support quality improvement

Case study: Asthma translations at Mid Yorks NHS

Challenges

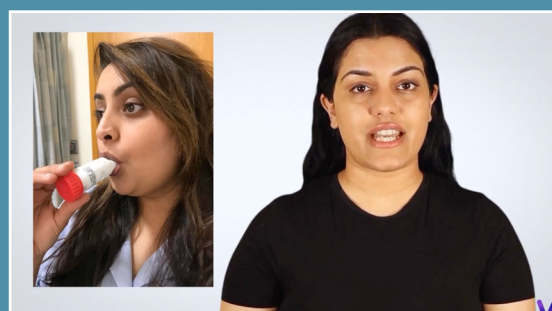
- Inequity of access to health information for those who do not speak/read English
- Poor representation of those from ethnic minorities on the Severe Asthma Register
- Cultural misunderstandings of asthma
- Emergency hospital admissions and occupied hospital beds related to low health literacy and poor self-management of asthma.

Solution

- Co-create a multi-lingual, multi-media suite of culturally relevant resources.
- Use VirtTuri AI technology and meaningful avatar characters to convey the messages
- Train and deploy Community Champions into the most deprived and culturally diverse areas.

Outcome

- The ability to cost-effectively visualise, and accurately translate essential healthcare advice has proven hugely popular with communities.
- There are early signs of a positive shift in understanding and adherence.



Equalities impact of digital tools

80% now consider equalities impact when introducing digital tools – up from 50% in 2019.

Steps taken to support digital access to health information

- Ensuring availability through multiple platforms (66%)
- Embed accessibility tools and options in websites (50%)
- Ensure access through multiple browsers (39%)
- Signpost to public libraries and other local services to support access (38%)

A digital-first NHS

77% of respondents felt a digital-first NHS has the potential to widen equal access to services and information if skills training is provided. This is up from 65% in 2019.

Despite the confidence in digital health 80% continue to provide information in non-digital formats.

Translated information

The number producing information for people with English as a second language fell to 44% from 57%. This might reflect the change in sector representation with fewer NHS trusts responding.

68% of responding trusts provided information for minority ethnic communities and non-English speakers.

Accessible information

Despite the statutory requirements of the Accessible Information Standard for public sector organisations, those providing information specifically for people with learning disabilities fell from 56% to 41%.

70% of NHS Trusts were providing information specifically for people with learning disabilities.

Case study: Digital exclusion and severe mental illness

Isle of Wight NHS Trust is tackling digital exclusion and its impact on people living with severe mental illness.

A mental health peer support digital coach is being recruited. They will raise awareness of mental-health-related reasonable adjustments in existing digital skills support services.

The role combines lived experience of mental health difficulties, training in peer support and understanding of available digital inclusion tools, resources and support.

The project addresses research findings that digital inclusion should be viewed as a wider determinant of health. It notes the need for increased awareness of digital exclusion amongst mental health staff and the availability of local digital skills support with a mental health peer support component.

Action on health literacy

75% of respondents had used PIF services to support expertise on health and digital literacy. They provided a wealth of information on measures taken to address health literacy needs of users.

These included:

- Extensive consultation with representative end users
- Creating a health literacy toolkit for staff
- Adding target reading ages to content guidance/strategy
- Providing information in alternative formats
- Introducing health-literacy guidelines for staff
- Removing jargon and using plain language
- Improving the accessibility of websites
- Increasing provision of automated translations
- Meeting the PIF TICK criteria
- Implementing Accessible Information Standard requirements
- Regular monitoring of peer support groups to identify areas of unmet need.

Examples of action

"We have a reading age of 11 and do not use any medical jargon (or when we have to, explain in plain English). We aim to make our information as simple and easy to understand as possible. We also make our information available in large print, audio, Easy Read and translated formats."

"We created Easy Read quick guides which have become our most-ordered resource."

"We are using new non-text based channels, health literacy guidelines for content creators, improved accessibility and navigation for the website, an involvement programme and use of peer-created content."

"We have undertaken actions relating to the PIF TICK action plan/assessment. We aim to include the end user and users with low digital literacy in the production of materials."

"We always have people from diverse backgrounds contribute to our information resource development plans."

"The communication team responsible for information production are aware of the importance of health literacy and that all our leaflets and resources are in plain English, jargon free where possible and in accessible formats."

PIF survey: Target reading age

PIF's guidance to aim for a target reading age of 9-11 is endorsed by information leads, according to a survey carried out in early 2022. It had 93 responses.

- 95% supported a reading age of 9-11.
- 59% have a formal policy on reading age (43% aimed for 9-11, 16% aimed for 12-14).
- Making information as accessible was seen as the main benefit of setting a target reading age (83%). Providing consistency for the team (47%), guidance to external writers (22%) and guidance for medical advisors (15%) were other benefits.
- Readability tools were used by 56% of respondents. The Hemingway App was the most popular tool, used by 38%.

Respondents were also clear on the limitations of readability tools and used wider user testing of text to check suitability for the target audience.

Resources

PIF Health and digital literacy survey 2019

pifonline.org.uk/resources/publications/health-and-digital-literacy-survey-201920

How-to guides

Translating health information

pifonline.org.uk/resources/how-to-guides/translating-health-information

Using plain language in health information

pifonline.org.uk/resources/how-to-guides/using-plain-language-in-health-information

Web accessibility

pifonline.org.uk/resources/how-to-guides/web-accessibility-a-quick-guide

Co-production and involving users

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

Communicating benefits, risks and uncertainties

pifonline.org.uk/resources/how-to-guides/communicating-benefits-risks-and-uncertainties

Posters

Health literacy matters

pifonline.org.uk/resources/posters/health-literacy-matters-infographic

Accessibility matters

pifonline.org.uk/resources/posters/accessibility-matters-poster

Translated health information matters

pifonline.org.uk/resources/posters/translated-health-information-matters

Inclusive language matters

pifonline.org.uk/resources/posters/inclusive-language-matters-poster

Co-production matters

pifonline.org.uk/resources/posters/co-production-matters-poster

Easy Read health information matters

pifonline.org.uk/resources/posters/easy-read-matters-poster

Webinars

Translating health information

pifonline.org.uk/resources/recent-webinars-and-events/translating-health-info

Creating Easy Read and image led information

pifonline.org.uk/resources/recent-webinars-and-events/creating-easy-read-and-image-led-health-information

Accessible information

pifonline.org.uk/resources/recent-webinars-and-events/accessible-information

Inclusive language in health information

pifonline.org.uk/resources/recent-webinars-and-events/inclusive-language-in-health-information

Digital accessibility

pifonline.org.uk/resources/recent-webinars-and-events/digital-accessibility

Co-production and involving users

pifonline.org.uk/resources/recent-webinars-and-events/co-production-involving-users

Training

We offer CPD-accredited training on writing health information and health and digital literacy. We also host monthly webinars. Register today: pifonline.org.uk/events-and-training

From attending these sessions on health and digital literacy, I feel really empowered and encouraged to take health literacy to the 'next level' in my organisation.

Join us

PIF is the independent UK membership body for people working in health information and support. We also run the only UK-wide quality mark for health information – the PIF TICK.

PIF represents more than 300 organisations across the NHS, voluntary, academic, freelance and commercial sectors. Our expert guidance on the production of high-quality health information supports an improved healthcare experience for patients and the public.

I think your organisation is brilliant and you are doing a great job. You really care about what you do.

PIF member

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