Health and Digital Literacy Survey 19/20

Executive Summary of a UK-wide survey of information producers and providers

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Texthelp is a PIF partner and has provided support to this project.

About PIF

The Patient Information Forum is the UK membership organisation and network for people working in health information and support. We are the independent voice of UK health information.

We represent more than 300 organisations across the NHS, charity, voluntary and commercial sectors.

Our expert guidance on the production of high-quality health information supports an improved healthcare experience for patients and the public.

PIF members work together to develop evidence-based solutions to today's health information challenges. The aim is to empower people to make informed decisions about their health and to improve outcomes.

PIF operates the PIF TICK, a UK quality mark for trustworthy health Information.

Health information is a therapy in its own right and should be accessible to all.

Our Vision

> "Everyone has access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care."

Our thanks to Texthelp for designing and producing the final report.

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In 2020, as the UK struggled with COVID-19, the need for user-friendly health information and access to digital healthcare came centre stage. The pandemic exposed existing health inequalities, hitting disadvantaged communities hardest. It emphasised the links between low health literacy, digital literacy and health inequality.

The need to provide health information people can understand and use to make decisions about their health goes beyond COVID-19. It applies to all health conditions, particularly those linked to inequality. These include obesity, COPD (chronic obstructive pulmonary disease), diabetes and cancer.

Health literacy

Many working age adults in the UK lack skills to understand and use information on health and wellbeing. Health literacy skills are lacking in 43% of the population and numeracy skills in 61%.
This gap between skills and the complexity of health information leaves millions excluded from making informed decisions about their health, compounding existing health inequalities.

43% of working age adults will struggle to understand instructions to calculate a childhood paracetamol dose.

PIF's 2015 market research demonstrated the impact on shared decision-making for people with long term conditions.

• 32% of adults found it hard to find general health information on their condition

• 20% lacked understandable information to support them in having a meaningful conversation with their doctor

Lower levels of health literacy limit people's ability to take part in shared decision-making, make informed choices about treatment and care and to understand and act on risk information. All these issues have an impact on people's behavioural response to the pandemic.

Digital literacy

COVID-19 accelerated the digital ambition of the NHS Long Term Plan. In the four weeks to 12 April 2020, 71% of routine GP consultations were delivered remotely, according to the Office for National Statistics (ONS). Secretary of State for Health Matt Hancock has said he wants this trend to continue and it is likely remote consultations will be part of the new normal.

However, nine million people lack digital skills, 8% are not connected and 66% with online access do not use the internet or digital tools to support their health.

In 2019 there was already concern that people with low health literacy and those without access, skills or motivation to use digital tools would be left behind in a digital-first NHS. Late in 2019 PIF ran a survey of its membership about their action on health and digital literacy. Its findings and recommendations have been made more urgent by the inequalities exposed by the pandemic.

Key survey findings

The 2019 survey was a repeat of our 2013 survey but questions were expanded to cover digital literacy for the first time.

Responses to the survey were received from 175 cross-sector health organisations operating in the UK, including NHS trusts, patient groups and the voluntary and private sectors.

These are the main findings from the 2019 survey.

The biggest perceived impact of low health literacy was people's lack of control over their own health (90%).

• 87% felt low health literacy led to difficulties in taking part in shared decision-making.

• 86% felt it led to problems communicating with healthcare professionals.

• Only 13% of respondents said their organisation had a health literacy strategy in place. This represented little progress from 10% in 2013.

• 12% said their organisation was in the process of developing a strategy.

• 40% stated they felt a strategy should be in place.

• The biggest perceived barrier to producing health information to address low health literacy was limited understanding of how to develop resources or services (73%).

• The number of respondents saying information producers did not realise the importance of health literacy rose from 53% in 2013 to 60% in 2019.

• 74% believed national health literacy strategies would help support quality improvement in health information.

• 67% believed NICE (National Institute for Health and Care Excellence) guidelines would help support quality improvement.

• The policy area of the NHS Long Term Plan perceived to be most affected by health literacy was health inequalities (89%).

• Only 50% had considered equalities impact when introducing digital services.

• 25% had undertaken digital skills training for service users.

• More than 65% believed a digital-first NHS had the potential to widen equal access to services and information.
But 43% believed the benefits would depend on skills training.

Commentary on findings

Most respondents (89%) recognise that low health literacy has an impact on health inequalities. Interventions to improve health literacy are recognised as one of the few evidence-based approaches for addressing and reducing health inequalities.

The vast majority of organisations producing health information see health and digital literacy as relevant and important to all patients and the public at large rather than only to specific groups of individuals.

However, the intention to ensure health information is geared to the health and digital literacy of the public is not backed by formal action.

It is disappointing only 13% of respondents said their organisation had a health literacy strategy in place. This represents little progress from 10% in 2013. It is also of real concern that only 50% had considered the equalities impact of digital tools.

Involving staff and volunteers

The challenges of health and digital literacy cannot be solved by individuals alone. Instead, there is increasing recognition that it needs a whole-systems approach.
It is therefore vital to engage staff and volunteers in all departments so that the challenges and potential solutions are understood by everyone.

One way of achieving this is through a health-literate organisation audit.
Staff and volunteers can be asked via a paper or online survey to indicate to what degree they are meeting a series of attributes of a health literate organisation.
They can also give examples from their work and suggest areas for improvement.

Organisations can tailor the attributes and examples to fit their own organisation and the services it provides.
Often the results show that people are already doing much more than they thought to address health and digital literacy challenges. This in itself is engaging and encouraging for the people involved.

Such an audit also provides a baseline from which improvements and changes can be measured in subsequent years.

Progress on health literacy

Most respondents work in health information teams of fewer than 10 people. They felt there was little recognition of the importance of health literacy at an organisational level. 40% felt their organisation should have a health literacy strategy.

Despite the lack of an overall organisational strategy, respondents had affected positive change. The proportion of organisations providing information for those with low literacy or numeracy increased from 35% in 2013 to 60% in 2019. There was also an increase in organisations providing information for black, Asian and minority ethnic (BAME) groups (39% to 58%) and people with multiple conditions (49% to 59%).

The biggest barrier to producing information addressing health literacy was 'limited understanding of how to develop resources' (75% 2013, 73% 2019). While people understand the concept of health literacy, there is less agreement about what constitutes health literate material in print or digital formats.

Digital and health inequality

More than 65% of survey respondents believe a digital-first NHS has the potential to widen equal access to services and information. But 43% believe the benefits depend on skills training.

It is of concern that only 50% of respondents reported their organisation had considered equalities impact when introducing digital services.

The policy area of the NHS Long Term Plan perceived to be most affected by low health literacy was health inequalities (89%).

The rapid adoption of digital solutions throughout 2020 and the inequalities revealed by the pandemic make it clear that health and digital literacy should be considered when developing information.

The overlay of low health and digital literacy needs will leave some people doubly disadvantaged.

75% of patients using Attend Anywhere software for virtual consultations in one trust found it difficult to find the correct waiting room for their appointment because of the medical language used to describe it.

Case study: Get Nottinghamshire Connected

This project set up by Nottingham and Nottinghamshire ICS aims to reduce the digital divide by ensuring socio-economic factors do not disadvantage access to digital health and care services across Nottinghamshire.

Through its introduction of a number of Digital and Social Inclusion schemes, Get Nottinghamshire Connected focuses on working and supporting the most excluded people across the region to help them gain the essential skills and confidence they need to start using technology and improve their digital health literacy.

Find out more at www.nottsnhsapp.nhs. uk/get-notts-connected/

Looking ahead and supporting change

National strategies have begun to incorporate health literacy as an enabler of other policy objectives. But this has not translated into the development of policies in other organisations within health. Small teams and organisations may not have time or resources to reflect at strategic level.

While there is widespread support among PIF members for the development of national strategies on health literacy in the four nations of the UK, it is recognised that health literacy needs to be built into all policy areas.

There is overwhelming support for quality improvement in health information through the development of NICE guidance on health and digital literacy to develop an evidence base of 'what works'.

Developing training and tools that are easy to apply and sharing good practice, will make it easier for organisations to become 'health literacy friendly'.

COVID-19 has shown unacceptable health inequality in the UK, action is needed now to close the health and digital literacy gap.

Recommendations

The recommendations are made in line with the five principles for the next phase of the COVID-19 response developed by National Voices, endorsed by PIF and other member organisations.

Five principles adapted for information producers

• Engage with users when developing information and digital resources.
• Make everyone matter.
• Confront inequality.
• Strengthen personalised care (particularly shared decision-making).
• Value healthcare and support equally.

1. UK National Health strategies
Incorporate health and digital literacy into health strategies of the four nations of the UK as a key enabler of shared decision-making, supported self-care and self-management and reducing health inequality. The strategies should encourage and support the development of 'health literacy friendly' organisations.

2. Organisations producing health information should aspire to become 'health-literacy friendly.'
Health-literacy friendly organisations make it easier for people to navigate, understand, and use information and services to take care of their health. They:
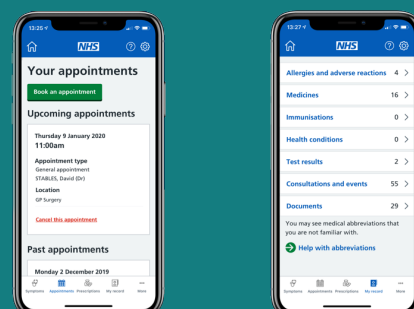• Use clear communication (verbal, written, digital).

• Create easy to use digital tools/websites, printed information and premises.

• Involve people in the development of information as routine and invite feedback.

• Train staff in health literacy.

3. NICE
Develop Guidelines on health and digital literacy to drive change and provide an evidence base. Ensure health and digital literacy is recognised in new and updated guidelines, with particular reference to shared decision-making.

4. Shared decision-making
Require the provision of 'health-literacy friendly' patient information (that conforms to standards) in planned national standards and guidelines on shared decision-making.

Case study: NHS Digital/NHS.uk
A complete overhaul of content on the public-facing website was undertaken as part of redevelopment to improve accessibility. Content is written for a reading age of eight years old. Content on the professional facing website is written for 12 year-olds.

People, even experts, prefer reading information in simpler terms. Jargon has been reduced, redundant text removed and reading age is considered for all new pages and posts.

5. PIF TICK

Trusted Information Creator

Develop specified UK standards on health literacy within the PIF TICK criteria related to:

•Reading age, use of plain language, and simpler language summaries to support people with lower literacy

•Numeracy age of material, use of natural numbers and icon arrays, fact boxes

•User involvement (co-production) in the development and testing of material.

•Availability of translated materials

•Recognised web accessibility standards WCAG 2.1 (see box on page 10)

Standards desirable for first 12 months with review after a year and a timetable to become mandatory.

User involvement or co-production means consulting and working with people who use health information and services from the start to the end of any project that affects them.

6. Good practice guidance

PIF to develop guide on 'How to Produce Health Literate Patient Information' and promote existing resources, knowledge and tools on health and digital literacy. Develop a health literacy checklist for information producers.

7. NHS repository for health literate and translated information

Create a central NHS repository for health literate information in English and other commonly spoken languages to help reduce health inequality in BAME groups exposed by COVID-19. Make NHS App and other national projects available in commonly spoken languages.

8. Digital health literacy

Raise awareness of the WHO definition of digital health literacy and the personal skills required.

'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.'

9. Community skills improvement

Support motivation and skills improvement through a partnership promoting and signposting health literate information in all formats to public libraries, schools, prisons, pharmacies and other community-based support.

10. Equalities impact of digital tools

All organisations should implement the Accessible Information Standard and, when developing digital projects, consider other reasons for digital exclusion and equalities impact including access, skills and motivation.

Case study: Public Health England
Public Health England planned to shift information about screening from print to digital format. They commissioned digital inclusion charity Citizens Online to carry out an equalities impact assessment and as a result retained some printed information for bowel cancer screening.

Find out more at: www.citizensonline.org.uk/digital-exclusion-in-population-screening-programmes/

Websites and WCAG 2.1

Design your website in accordance with WCAG 2.1 global accessibility guidelines from the World Accessibility Initiative (WAI).

• Ensure every element of your website is discoverable (perceivable).

• Ensure your website is fully operable.

• Ensure the content on your website is health literate.

• Ensure your website is robust (can be accessed from different devices and browsers).

• Ensure your digital content is accessible to all your audiences, including people with low digital skills, dyslexia, visual impairments and people who speak English as a second language.

• Learn best practices from other organisations across various industries.

Join us

PIF is the independent UK membership body for people working in health information and support. We operate the PIF TICK, the UK-wide quality mark for health information.

We have more than 1,000 members in 300 cross-sector organisations. These include national charities, the NHS, commercial, government, freelance and academic sectors. We use the insight and support of our membership to lobby governments in support of our vision.

Our Vision

Everyone has access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care.

Our Partners

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