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Finding Credible Healthcare Information

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Trustworthy health information is a cornerstone of patient/citizen participation in care delivery. Moreover, as the current pandemic shows, it is key to protecting both personal and collective health. The Patient Information Forum strives for both improving the quality of available health information and eliminating the health- and digital-literacy gap.

Key Points

- Access to high-quality health information is an essential element of individual and public health, especially amid the COVID-19 pandemic.
- The PIF TICK scheme provides a framework for health information producers to ensure reliability of their messages.
- There has been some progress in the recent years in how the health- and digital-literacy gaps are addressed by health organisations, but more work is needed.
- PIF has created a list of recommendations on improving health and digital literacy across the UK.

Supporting and driving up quality and trust in health information has always been at the heart of the Patient Information Forum (PIF) and it has never been more important to signpost the public to trustworthy health information than in the current crisis. We would like to believe that today's patient is armed and fully informed to engage in their care delivery. But is this really the case?

Unfortunately, the current COVID-19 pandemic suggests otherwise and serves to reinforce some of the existing shortcomings in the system, which must be addressed if we are to increase people's ability to stay healthy and manage illnesses effectively, giving them a better quality of life.

Until now, many may have regarded the need for high-quality healthcare information solely as an intervention to guide and support people through an illness, surgery or living with a long-term condition, but the current pandemic has highlighted how vital it is for everyone to have access to accurate, evidence-based, up-to-date and culturally appropriate information to safeguard our personal and collective health.

The COVID-19 crisis has shown how easy it is for unreliable and untrustworthy information to make it into mainstream through social media. We need to address how we help patients and the public to find high-quality health information they can trust. We need to ensure people have confidence in the health information they find on the internet or in community settings.

In July 2020, a survey by PIF of over 800 people found that one in three had delayed accessing care, 75% of these because of COVID-19 concerns (PIF 2020a). Despite the easing of restrictions, more than half (57%) of all respondents were concerned about attending future appointments. Just under half of respondents had been shielding.

Fear of catching and becoming seriously ill with COVID-19 outweighed concerns about existing health conditions. A lack of trustworthy information and conflicting guidance emerged as the key concerns and barriers to seeking appropriate medical help, even greater than age, gender or an underlying health condition.

Respondents expressed a clear desire to know where they would be seen, whether they would be seen face to face, how they would access facilities upon arrival, what doctors and nurses would be wearing, whether or not they themselves would be wearing a face mask and how they would be kept safe from the threat of the virus.

Patients who are avoiding medical appointments and preventative care out of fear of contracting COVID-19 could be putting themselves at risk of developing a serious illness.

Providing people with clear information about the measures being put in place to protect them will allow them to weigh the risks and benefits of addressing their health needs versus the risk of contracting the virus.

Lack of Trust and Need for Inclusion

The COVID-19 crisis has highlighted the need for people to have the confidence and trust in the information being provided and the importance of health and digital literacy in ensuring information is inclusive.

To help address these issues and to provide a solution,

PIF has been working with colleagues across the voluntary, public and private sectors to create a quality standard, the PIF TICK.

Consumer research by PIF found 80% of the public would look for a quality mark for health information they could trust. Evidence, plain English and trained staff were the top three criteria for quality health information identified by the public, although all criteria were supported.

But COVID-19 has particularly highlighted the importance of clear messaging, which is culturally appropriate and speaks directly to everyone to help mitigate fears and reduce anxiety. The use of culturally specific imagery and content using voices of communities with lived experience is needed to shape future public messaging. These issues are addressed in the recent Public Health England's (PHE) report *Understanding the impact of COVID-19 on BAME communities* (PHE 2020) and their recommendations apply both to COVID-19 and information on non-communicable diseases associated with inequality, including diabetes, heart disease and obesity. Work already taking place includes an ethnic minority influencer programme and key messages being translated into local community languages but more action is needed including a more streamlined approach nationally and locally to improve translation (Race Disparity Unit 2020).

Ensuring information is inclusive and does not reinforce health inequalities is essential. Involving the community and users in the development and creation of the content, communications and marketing will increase the reach, strengthen the impact of the messages, and so help improve overall health.

These elements are all a key part of the process for producing quality health information and achieving the PIF TICK, a sign for the public that they can trust what they are reading. PIF has produced guidance on all aspects, including user engagement, but we too are committed to continuous improvement and we will undertake a review of our own guidance to make sure it is fit for purpose.

Forty six organisations have joined the PIF TICK scheme since it opened in April 2020 and are in the process of certification. We would encourage as many of you as possible to take a look at the scheme and join us in getting one step closer to giving patients and the public confidence to make the necessary changes and improvements to their health based on trusted information.

The PIF TICK logo can be applied to leaflets, websites, apps and videos or any form of health information that has gone through an organisation's certified production process. To be awarded the PIF TICK an organisation must undergo an assessment to show its production process meets ten criteria addressing issues of accessibility, reliability and user engagement.

The ten criteria for trustworthy health information are:

1. Information is created using a consistent and documented process
2. Staff are trained and supported to produce high-quality information
3. Information meets an identified consumer need
4. Information is based on reliable, up-to-date evidence
5. Patients are involved in the development of health information
6. Information is written in plain English
7. Print and digital information is easy to use and navigate
8. Users can give feedback on information
9. Information is promoted to make sure it reaches those who need it
10. The impact of information is measured.

Charter to Tackle Inequality

The COVID-19 pandemic has exposed existing health inequalities, hitting disadvantaged communities hardest, and emphasised the link between low health literacy, digital literacy and health inequality.

PIF is calling for all health information providers to sign up to a health and digital literacy commitment charter.

The call to sign the charter comes following the recent publication of PIF's Health and Digital Literacy Survey results, which found that the gap between skills and the complexity of health information is leaving millions excluded from making informed decisions about their health (PIF 2020b).

By signing the charter, organisations are recognising the importance of health and digital literacy and committing to becoming 'health literacy friendly'. In the first month, more than 30 organisations made this important public commitment.

Jonathan Berry, National Lead for Health Literacy at NHS England and Improvement, stated: "Health literacy has a high impact on people's health. It can affect, among other things, how they access and use services, manage a long-term condition, take medication and live healthily. It is also inextricably linked with health inequalities."

Progress has been made since PIF last conducted the survey in 2013 (PIF 2013) with 60% of organisations providing information for those with low literacy or numeracy, compared to 35% in 2013, and 58% are providing information for BAME groups, compared to 39% in 2013.

However, there is more work to be done with only 13% of respondents saying their organisation had a health literacy strategy in place. This represented little progress from 10% in 2013.

The 2019 survey (PIF 2020b) also asked how health information providers were tackling digital literacy, timely as just months later COVID-19 would accelerate the digital ambition of the NHS Long Term Plan. Only 50% of survey respondents had considered equalities impact when

introducing digital services.

In the four weeks to 12 April 2020, 71% of routine GP consultations in the UK were delivered remotely, according to the Office for National Statistics (Walker 2020).

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.

To help stop this 'digital divide' increasing health inequalities further, PIF is recommending all organisations consider the equalities impact when introducing digital services.

Throughout the survey, a lack of recognition of the importance of health and digital literacy at an organisational level emerged as a key concern (PIF 2020b):

- 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 do not realise the importance of health literacy rose from 53% in 2013 to 60% in 2019.

If we are serious about tackling the health inequalities revealed by the COVID-19 pandemic, then it is important for all organisations producing health information to become health- and digital-literacy friendly. Health information must be clear, consistent and accessible in all its formats if people are to make informed decisions about their health. Ensuring information is inclusive, culturally appropriate and co-produced are all key elements in making content health-literacy friendly.

Health and Digital Literacy Recommendations

PIF, in partnership with an expert panel, has published the following recommendations to improve health and digital literacy across the UK:

1. **U.K. 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.
2. **Organisations producing health information:** Should aspire to become 'health-literacy friendly'.
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 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.
5. **PIF TICK:** Develop specified UK standards on health literacy within the PIF TICK criteria.
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 translated information:** Create a central NHS repository for health literate information in English and other commonly spoken languages, to 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.
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 consider other reasons for digital exclusion/equalities impact including access, skills, motivation when developing digital projects.

The expert panel which advised on recommendations included members from a number of organisations, e.g. PIF, NHSE, Health Education England, etc. (full list).

Conflict of Interest

For the Covid Choices survey, PIF received partial financial support from Norgine Ltd, an existing partner organisation. Hill and Knowlton provided pro bono support for quantitative data analysis of the survey. For the Health and Digital Literacy survey, PIF partner TextHelp provided pro bono support to design an accessible PDF of the survey report. ■

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