



**Patient
Information
Forum**

Health & Digital Literacy Survey 2019/20

Sophie Randall, Head of Strategy and Partnerships

About the survey

What? A repeat and update of a survey we ran in 2013, included digital literacy for the first time.

Why? Health literacy is vital to success of personalised care.

How and where? Online survey via SurveyMonkey promoted to the PIF membership and our network.

When? For three weeks during health literacy month 2019. Expert group established to review the findings and make recommendations, originally scheduled for March 2020, delayed by pandemic.

Health and Digital Literacy Survey – Findings and Recommendations

only **13%** 

of respondents said their organisation
had a health literacy strategy in place

*This represented little progress
from 10% in 2013.*

Health and Digital Literacy Survey – Findings and Recommendations

58%



**of survey respondents are providing
information for BAME groups**

This is compared to 39% in 2013.

Health and Digital Literacy Survey – Findings and Recommendations

only **50%** 

of survey respondents had considered equalities impact when introducing digital services

Recommendations

Made in line with the 5 principles defined by National Voices and endorsed by PIF for the COVID recovery.



Expert group – representing PIF's cross sector members

Julia Bell, Patient Information Consultant

Jonathan Berry, NHS England

Stacey Budd, Gloucestershire Hospitals NHS Foundation Trust

Ruth Carlyle, Health Education England

Louise Coghlin, PIF Advisory Group

Jaina Engineer, Crohn's & Colitis UK

Alexis Farrow, Connected Nottinghamshire

Bob Gann, Independent Consultant on Digital Exclusion

Aiden Kelly, TextHelp

Jo Protheroe, GP Health Literacy UK

Recommendation 1

Governments of UK's four nations

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.

Recommendation 2

Information Producers to become health literacy friendly

Organisations producing health information should aspire to become 'health literacy friendly'.

- Use clear communication (verbal, written, digital).
- Create easy to use digital tools/websites, printed information and premises.
- Co-produce: Involve people in the development of information as routine and invite feedback.
- Train staff in health literacy.

Recommendation 3

NICE guidelines on health literacy

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.

Recommendation 4

Shared Decision Making – embed health literacy in standards

Require the provision of 'health-literacy friendly' patient information in planned national standards and guidelines on shared-decision making.

Recommendation 5

Trusted
Information
Creator



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PIF TICK: Quality Mark Criteria

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, 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

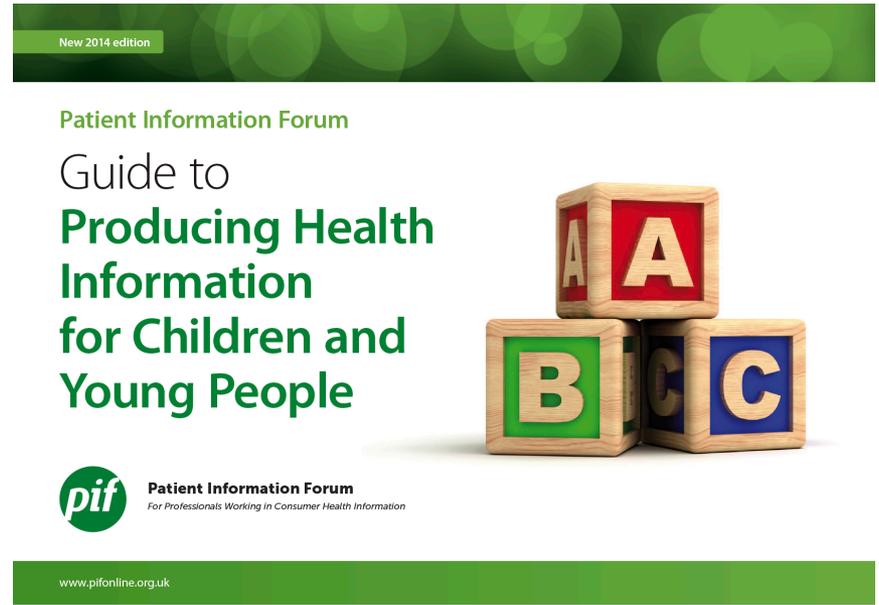
Standards desirable for first 12 months with review after a year and a timetable to become mandatory.

Recommendation 6

PIF Good Practice Guide

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.



Recommendation 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.

Recommendation 8

WHO definition of digital health literacy

Raise awareness of the overlay between health and digital literacy using WHO definition:

'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.'

Recommendation 9

Community skills improvement

Support motivation and digital 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.

Recommendation 10

Equalities impact assessment 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.

Next steps and why now?



Covid Choices

1 in 3 
delayed healthcare or treatment

*I did not start a new medication
as it would involve weekly blood
tests and I was shielding.*



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COVID-19 and health inequality

- Pandemic has revealed massive health inequalities.
- *Health literacy is inextricably linked to health inequality according to 87% of respondents.*
- Pandemic has massively accelerated digital change.
- *9 million people (16%) are unable to use the Internet or their devices without assistance.*
- Pandemic has created a moment for change.
- *PIF members have risen to the challenge of getting trustworthy information to users, working quickly and using different methods.*

1 in 2



patients most worried about their risks from COVID-19 said they lack trusted information

1 in 5



patients least worried about their risks from COVID-19 said they lack trusted information

Is your organisation health and digital literacy friendly?

- ✓ Assess the equalities impact of digital projects
- ✓ Easy to understand information
- ✓ Easy to use print and digital projects
- ✓ Co-produced with users
- ✓ Trained staff in health literacy



Sign the PIF charter today



Questions

