Patient Information Forum

The value of trusted health information

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Information challenges: Ipsos poll of 2,000 adults in 2024

- Around half of UK adults struggle to find health information they can trust.

- 8 in 10 people say trustworthy information would help them manage and live with a long-term condition (LCT).

- Only 1 in 10 people with LCTs signposted to a condition-specific patient organisation by health professionals.

- But health charities are highly valued and trusted by those who use them.

Survey of users of PIF member organisations

In 2024 we asked 10 PIF member organisations to share a survey on health information with users.

We had just over 200 responses. But there are weaknesses in the data.

- Barriers to sharing the survey, for example data protection policies.
- Public survey 'fatigue'.
- 65% responses were from the same charity.
- Most respondents were white, middle aged, well educated women.

Information seeking behaviours and preferences

1 in 2 people had searched for health information in the last week

1 in 3 in the last month

Top 5 formats and sources (respondents asked to select 3)

- 8 in 10 preferred to access information online
- 5 in 10 via the NHS app
- 4 in 10 via an email of text from their doctor with links to supportive information
- 3 in 10 leaflets from their doctor or nurse
- 2 in 10 social media posts

People's experience

'I tend to use trusted websites or apps to look something up. What is really useful however, is information from GP following an appointment.

The younger GPs use this method - for example sending a text after an appointment with information or website. I have noticed that the older GPs do not do this.

It makes the patient feel that they are being listened to and their issues being considered even after leaving the consultation.

My consultants have never followed up an appointment with further support or information.'

Trusted health information has an impact

8 in 10 agreed information provided by the organisation helped manage their health.

- 'When everyone else had 'given up on' my breathing issues, Asthma UK supplied me with information and advice which led to an eventual solution.'

- 'I've used Asthma and Lung UK's online Breathing Class since I recovered from Covid. It helped me physically and mentally to deal with my asthma. It is very supportive.'

Trusted health information has an impact

- 'The detailed information has given me a broader insight into my condition and enabled me to ask more pertinent questions at my hospital appointments'.

- 'National Rheumatoid Arthritis Society regularly have Facebook live events with healthcare professionals giving a talk and answering questions. It makes a massive difference'.

- 'I discovered the charity Tommy's. I found the support personally helpful when experiencing my baby loss.'

Information, appointments and confidence

9 in 10 seek health information before making a GP appointment or hospital appointment.

9 in 10 go to appointments with questions prepared.

8 in 10 feel confident enough in their knowledge to discuss their treatment with their care team.

8 in 10 check advice or treatment recommendations made by HCPs.

6 in 10 say their views are taken seriously by health professionals or that they are supported to make treatment decisions.

People's experience

- 'I'm always fully prepared for appointments so I can ask pertinent questions. Often we are making decisions about my care so being prepared and armed with questions gives me comfort that decisions are well informed.'

- 'I always see if I can find an answer myself rather than take up GP time. I also find it useful to research likely outcomes if I do get an appointment, including the latest drugs and treatments available.'

- 'Some are very good at listening, but on the whole I have to be very direct and forceful to get what I need from the appointment.'

- 'Don't feel listened to or respected, especially if I ask about what they've said, they seem to feel I'm arguing with them, when I'll I want is to understand more clearly.'

Comparisons with Knowledge Is Power

Findings suggest health charities have an impact on their users' wellbeing and their ability to manage their health.

- Improved confidence in managing their health.

  - More confident in the ability to navigate information and less in need of health information verification.

- Feel more confident in their knowledge and ability to take part in decision making and but do not feel not more listened to.

- Boosted by wider support, people feel less isolated and alone.

- Supports recommendations from Knowledge is Power. People want to be signposted to trusted sources by NHS.uk, NHS App and HCPs. They benefit from trusted health information.

Changes in the information environment

The environment has changed significantly since we gathered data. This makes signposting from the NHS, HCPs and libraries more vital.

- Changes in search analytics, impact of genAI, introduction of Google AI search summaries have been accompanied by reduction in traffic to health charities.

- There are concerns about the quality of Google AI summaries - this technology is in development.

- Removal of fact checking on social media platforms.

This is making it harder for people to find trusted sources independently.

Next steps

Continue to lobby for the recommendations of Knowledge is Power. Presenting to Ofcom next month.

Starting a project with NHS England to improve the usability of the PIF TICK website for public libraries and health librarians.

We are also hoping to work in closer partnership with Libraries Connected on signposting trusted information to support health literacy.

Working with member charities to share feedback on Google AI search summaries. PIF aiming to:
- act as a conduit for member feedback to Google
- explore localisation of AI search summaries
- opportunity for Google to share new best practices on search optimisation with members

If you want to get involved, please get in touch.