

Knowledge is Power

A survey of 2,000 UK adults using the Ipsos KnowledgePanel

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About Patient Information Forum (PIF)

The Patient Information Forum (PIF) is the independent membership body for people working in health information and support. We are the independent voice of UK health information. PIF runs the only quality mark for print and digital health information – the PIF TICK. PIF has promoted access to trusted health information for patients, carers, the public and healthcare professionals for more than 25 years. Extending our influence and impact is only possible with the support of our members and the partnerships we build with like-minded organisations. Our vision is for everyone to have access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care. For more information visit www.pifonline.org.uk.



About Ipsos

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Foreword

A person's right to information to inform their care is enshrined in the NHS Constitution¹.

The results of PIF's last survey in 2015², found people faced significant challenges with access to information at diagnosis and when discussing decisions about their care.

While some aspects of the health information landscape have transformed, these challenges persist today. Finding trusted health information has become ever more critical in an era of misinformation and there are inequities in access which compound health inequality.

Access to credible and user-friendly health information is critical to improve the health and wellbeing of people in the UK. Health information supports people to live healthier lives and prevent ill-health. It helps them self-care and use NHS services appropriately.

Credible information supports people's health decisions, from childhood vaccinations to joint replacement surgery. For people with long term conditions, it is a core element of care.

Our 2024 survey gives a clear view of how people want to access health information and the challenges they face. Resolving these issues will ensure everyone gets the information they need, supporting the prevention agenda and contributing to the delivery of positive health outcomes for all.



Sue Farrington Chair, PIF

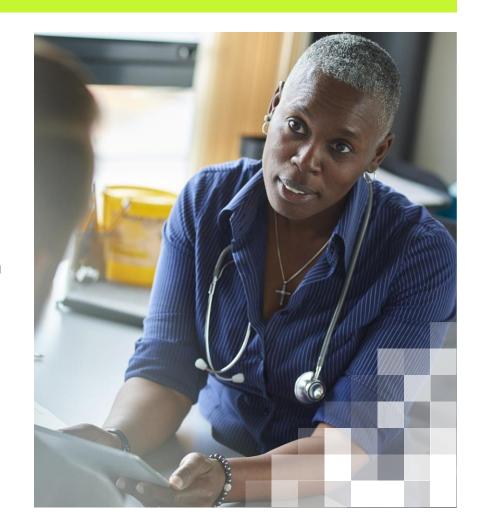
Health information for all

COVID-19 confirmed the scale of health inequalities³ and the extent of health disinformation⁴.

Inequalities in access to information persist today, particularly for ethnic minorities and those with health literacy challenges^{5,6,7}.

GPs are seen as a trusted source of health information. But 1 in 6 people say their views are not taken seriously by their health professional. This rises to 1 in 4 for ethnic minorities.

While there has been some improvement in patient-professional communication since 2015, the NHS capacity crisis is likely to have limited progress.



Knowledge is power

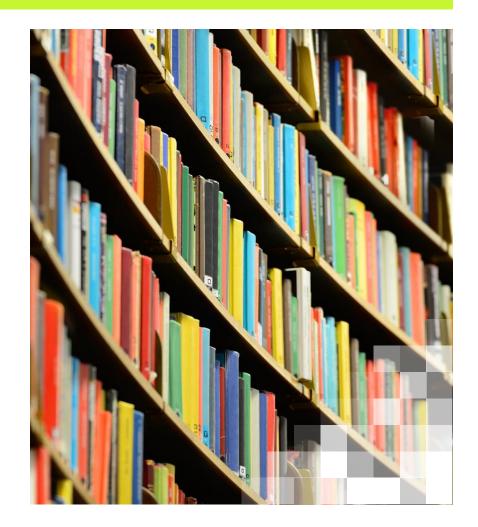
While most UK adults find it easy to find health information online, less than half feel they can trust it.

Misinformation has critically undermined the increased availability of health information on digital channels since 2015.

1 in 10 adults have been personally affected by misinformation at a time when access to NHS care is difficult.

Our data shows 2 in 3 UK adults now state independent verification of health information would increase trust.

The NHS and healthcare professionals remain the most trusted sources of health information.



A right to health information

4 in 5 UK adults agree that access to trusted health information would help them manage their health. This would support the prevention agenda of the NHS.

But healthcare professionals are not consistently providing health information.

Only 1 in 10 people with long term conditions report being signposted to patient organisations, yet these are highly trusted by their users.

Barriers preventing NHS signposting to external sources include lack of capacity, lack of training and inconsistent trust governance procedures.

These barriers must be removed. There is a need to activate the right to health information.

Case Study

A Health Foundation study of 9,000 people with long term conditions found those who felt confident to manage their health had 18% fewer GP visits and 38% fewer A&E visits⁸.

https://pubmed.ncbi.nlm.nih.gov/30139822/ #full-view-affiliation-1

Health information embedded in the digital NHS

Credible information from certified sources should be embedded in the NHS App and face-to-face interactions across the NHS^{9,10}.

National signposting would support the public to care for their health and reduce pressure on NHS services and health professionals.

It would reduce duplication at local level, provide a consistent experience for patients and allow NHS information teams to focus on the specific needs of their communities.

Local information will be a critical success factor in shifting care from hospital to community and creating a health-literacy friendly NHS people can navigate with confidence.

Case Study

Only 3 in 10 respondents to a survey by Kidney Care UK were told how to contact kidney charities for further support. The charity called for signposting from the NHS App so people are empowered to make informed choices.

https://kidneycareuk.org/about-us/policy-updates/failureto-recognise-the-seriousness-of-ckd-is-costing-lives/

Certified health information to tackle misinformation

Failure to provide information allows harmful misinformation to flourish. 1 in 10 say they have been affected by online misinformation, rising to 1 in 5 for ethnic minorities.

The shift from analogue to digital must include support for people to access digital health, ensuring they find safe digital spaces that meet their needs.

The PIF TICK launched in 2020 to provide verification of health information. More than 140 organisations are certified.

It is gratifying to see public awareness of the PIF TICK increasing to 1 in 10 among young people.

Trusted Information

Creator

Patient Information Forum

Case Study

NHS England is partnering with public libraries to improve access to the NHS App and NHS.UK.

The campaign also signposts websites with trusted health advice. The PIF TICK Directory is part of the toolkit.

The pilot aims to increase digital inclusion and empower people to take an active role in their health.

PIF would like to see similar partnerships across the UK in schools, prisons and other settings.

https://digital.nhs.uk/services/nhsapp/toolkit/libraries/useful-websites-with-trustedhealth-advice

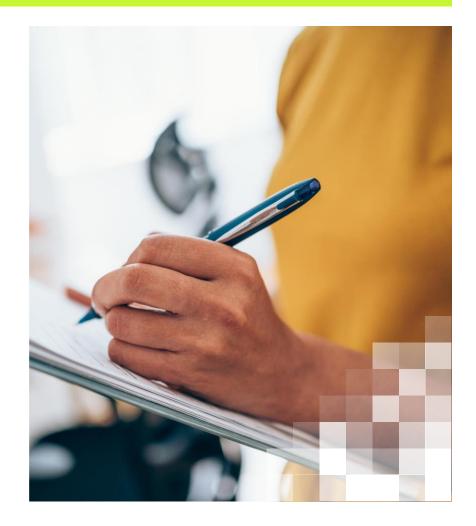


Research background

This research was conducted by Ipsos in partnership with the Patient Information Forum (PIF).

A cross-sectional, nationally-representative survey was conducted with 2,003 adults in the UK from May-June 2024 using the Ipsos KnowledgePanel. The survey captures how adults in the UK access health information, trust health information, and the impact this information has, particularly on people living with long-term health conditions.

The findings of this research will be used to identify areas for PIF and its partners to improve access to credible health information across the UK.



Sample

The Ipsos KnowledgePanel is a random probability survey panel. The KnowledgePanel does not use a quota approach when conducting surveys, which results in a nationally representative sample.

Instead invited samples are stratified when conducting waves to account for any profile skews within the panel. The sample was stratified by country and education.

A total of 3,871 panelists in the United Kingdom aged 18+ were selected and invited to take part in the survey. Of these, 2,003 respondents completed the survey – a response rate of 52%.

In addition to reporting overall responses, data were analyzed to identify differences by age, gender, ethnicity (white or ethnic minority – Black/African/Caribbean, Asian, or other), and education level.





Study results



Adults in the UK are struggling to access health information they can trust.



Less than half of all adults in the UK feel they can trust health information they find online

7 in 10



UK adults (69%) find it easy to find health information **online**.

However, just

45%



feel they can trust the health information they find **online**.



Base: All respondents (n= 2003)



1 in 4 adults with a long-term condition in the UK do not feel they can trust online health information

In 2024,

1 in 4



UK adults (26%) with a **long-term condition** do not feel they can trust the health information they find **online**.

In 2015,

1 in 3



patients surveyed (32%) found it difficult to access trustworthy information on their condition².



Base: All respondents (n= 2003)



Adults in the UK have more trust in offline health information, but access is an issue

Only...



UK adults (26%) find it easy to find health information offline.

But...

53%



feel they can trust the health information they find offline.

Older adults



aged 55 years and older do not feel they can trust the health information they find...



a online (43%)

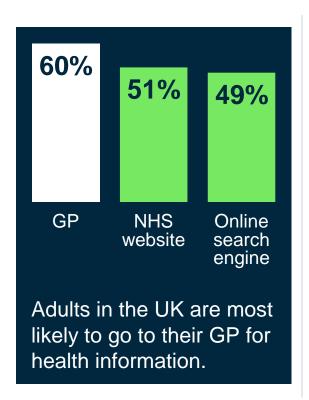


Base: All respondents (n= 2003)

While healthcare providers are the most common sources of information, there are signs of a lack of trust.



GPs are one of the most common sources of health information, but there are signs of a lack of trust





Base: All respondents (n= 2003)

Q4: When looking for health information for yourself, which of the following, if any, would you usually go to?

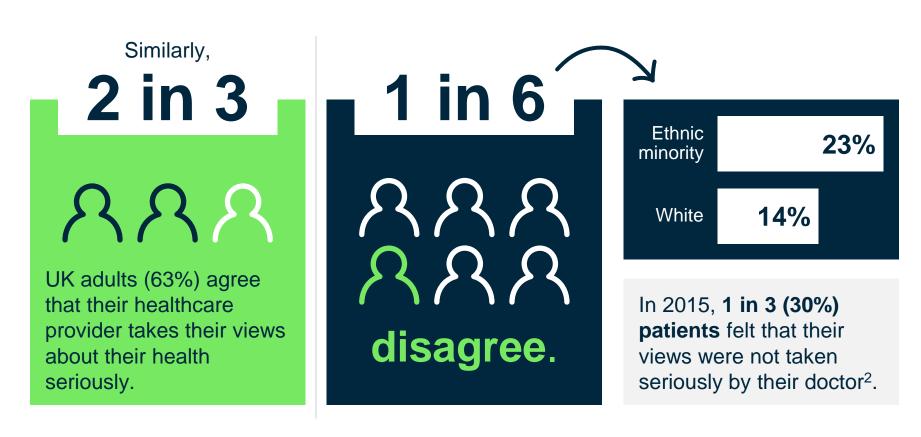
Q5: And which of the following sources would you say you trust the most for health information? Please select up to three sources which you trust the most?

1 in 6 UK adults say they do not feel listened to, up to 1 in 4 for ethnic minorities



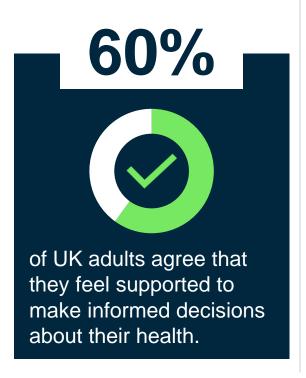
Base: All respondents (n= 2003)

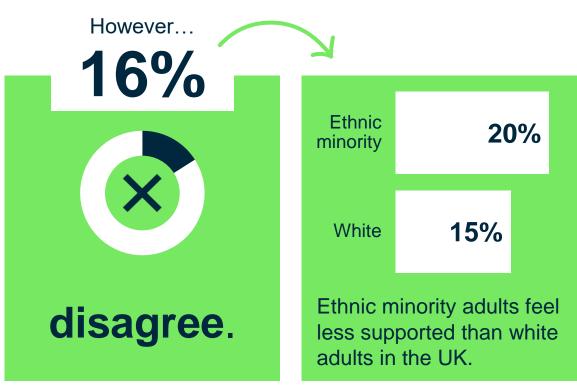
1 in 6 UK adults feel their healthcare provider does not take their views about health seriously. This is higher amongst ethnic minorities



Base: All respondents (n= 2003)

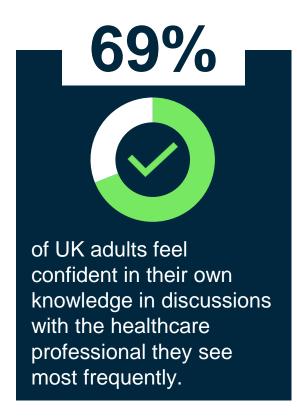
A significant minority of UK adults do not feel supported to make informed decisions

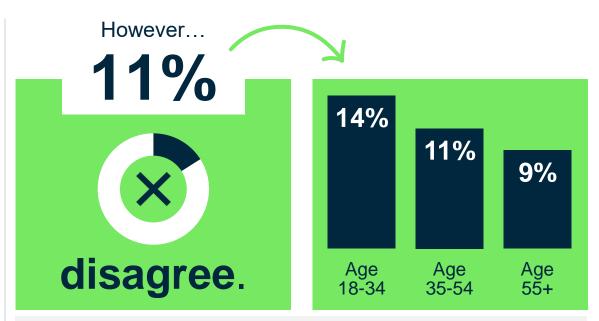




Base: All respondents (n= 2003)

A significant minority of UK adults do not feel confident discussing their health with their provider

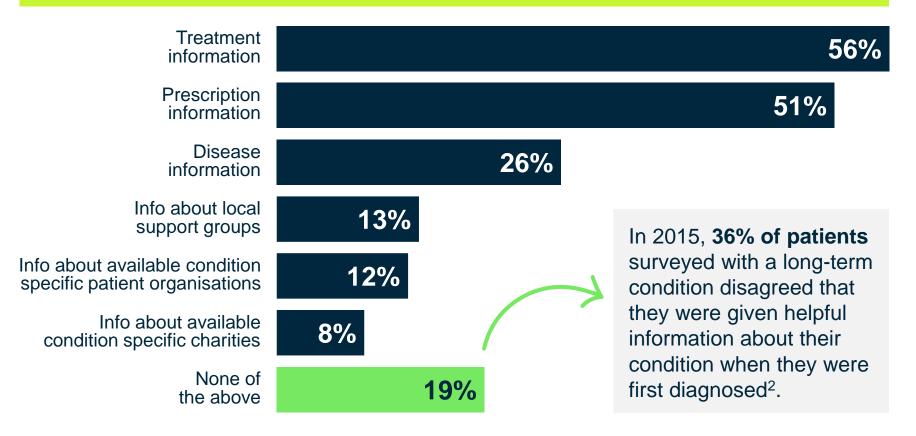




This is lower compared to research in 2015, when **20%** of patients surveyed disagreed that they had enough information to feel confident in discussing decisions about their care with their doctor².

Base: All respondents (n= 2003)

1 in 5 UK adults with long-term health conditions have not been given any information from their HCP since their diagnosis



Base: All respondents (n= 1235)

Q6: You previously said that you live with one or more chronic or long-term condition. For this question, please think about your main diagnosis. Since your main diagnosis, what health information, if any, have you been given by your doctor or another healthcare professional regarding this condition?

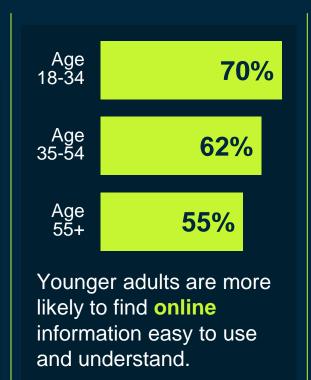
There is a clear need for trustworthy, accessible and easy-to-find information.

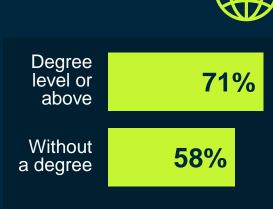


Online information is perceived as better than offline information in terms of ease of use and accessibility



of UK adults agree that online health information is easy to use and understand.





Those educated to degree level or above are more likely to find **online** information easy to use and understand.

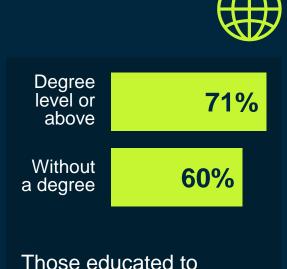
Base: All respondents (n= 2003)

2 in 3 UK adults agree that online health information is delivered in an accessible format



UK adults (63%) agree that the health information they find **online** is delivered in a format they find accessible*.





degree level or above are more likely to agree with this statement.

Base: All respondents (n= 2003)

^{*} E.g. as Easy Reads or translated into their preferred language.



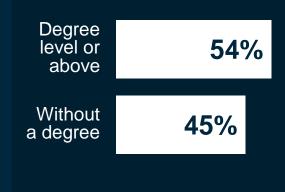
Just under half of UK adults find offline health information easy to use and understand





is easy to use and

understand.



Those educated to degree level or above are more likely to find **offline** information easy to use and understand.

Base: All respondents (n= 2003)



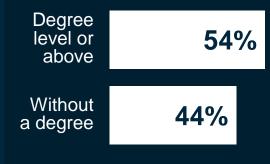
Similarly, about 1 in 2 respondents agree that offline health information is delivered in an accessible format



1 in 2



UK adults (47%) agree that the health information they find **offline** is delivered in a format they find accessible*.



Those educated to degree level or above are more likely to agree with this statement.

Base: All respondents (n= 2003)

Q3: To what extent do you agree or disagree with each of the following statements about finding health information offline? * E.g. as Easy Reads or translated into their preferred language.



UK adults report being affected by misinformation both online and offline





1 in 10

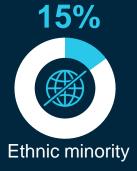


UK adults (11%) say they have been personally affected by **online** misinformation relating to their health.

1 in 10



UK adults (8%) say they have been personally affected by **offline** misinformation relating to their health

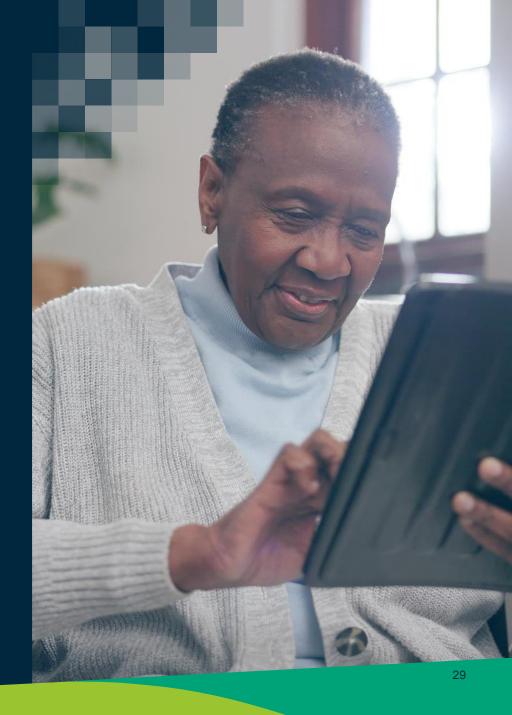




Base: All respondents (n= 2003)

Q9: To what extent do you agree or disagree with each of the following statements about health misinformation? By misinformation, we mean incorrect or misleading information, which may exist without specific malicious intent. Please think about health information you may find online. **Q10.** Please think about health information you may find offline.

Verification of quality online health information is critical for adults with long-term health conditions in the UK.



Trust in condition-specific patient organisation websites is high among users

100%

of people using health information patient organisation websites say these are in their top three most trusted sources.



74%

say they find it easy to assess whether to trust the health information they find there.

8% ti



say they are not sure if they can trust the health information they find there.

Base: All respondents (n= 403)

Q5. And which of the following sources would you say you trust the most for health information?

Q12: You previously said that you go to a condition-specific patient organisation website to look for health information. To what extent do you agree or disagree with each of the following statements about finding information on this website?

Having access to trustworthy information would help those with a long-term condition manage their condition



Base: All respondents (n= 1235)

Q8. For this question, please think about your main diagnosis. To what extent do you agree or disagree with the following statement: Having access to trustworthy information would help me manage my condition?

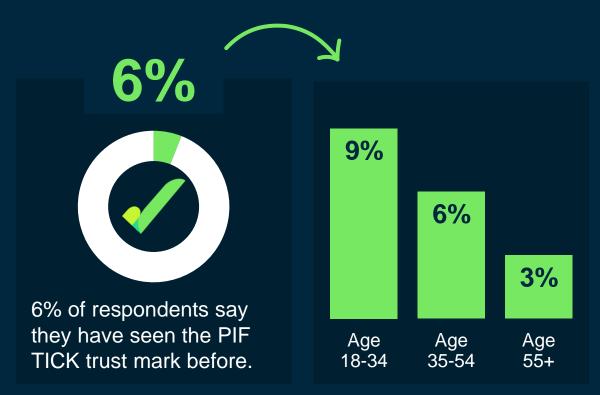
The independent verification of health information would help increase trust for the majority of adults in the UK



Base: All respondents (n= 2003)

Q13. To what extent, if at all, would the independent verification of health information increase or decrease your trust in a source of information?

There is already some recognition of the PIF TICK among UK adults, with opportunity to grow





Base: All respondents (n= 2003) **Q14.** Have you ever seen the PIF TICK trust mark for health information?

"Health information should be easy to understand, be available and reliable for everyone.

Dr Nighat Arif GPPIF TICK ambassador,
broadcaster, and trusted health
information creater



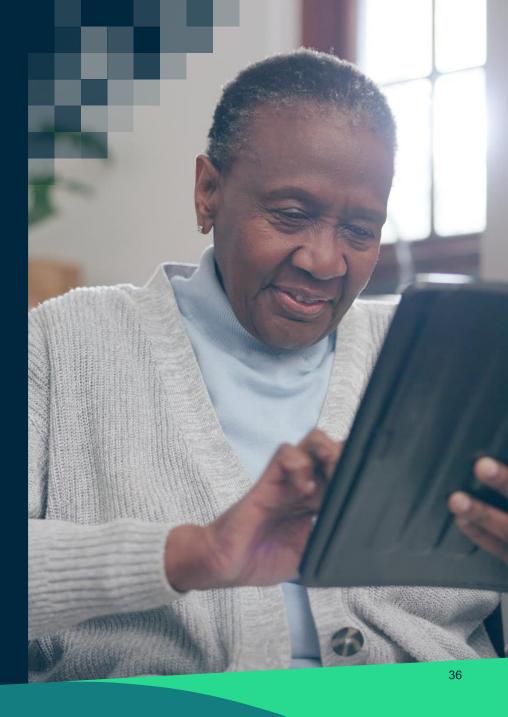






Recommendations

A right to health information



A right to health information:

Health information is provided as a core part of patient care

Credible health information should be integrated into care pathways. It is a key intervention for improving outcomes, preventing ill health and is a core part of patient care.

The use of personalised patient learning platforms should be expanded as a key lever to empower people to take care of their health.

These should be promoted by health professionals and linked to the expansion of national NHS apps and the single health record.

National NHS apps should signpost people with long term conditions to national patient organisations providing information and support as a standard part of care.

Case Study

The National Rheumatoid Arthritis Society's Right Start service runs in 205 hospitals.

Patients have a 45-minute call with the NRAS helpline. They are sent a resource pack tailored to their needs and can access peer support.

More than 2,000 people have been referred in two years. More than 9 in 10 rated the service as good or excellent.

A full evaluation is underway.

https://nras.org.uk/resource/about-right-start/



Tackle misinformation:

Through robust content standards and effective signposting

The PIF TICK sets standards for high quality health information. It is endorsed by the World Health Organization (WHO)¹¹ and the Academy of Medical Royal Colleges¹² and is the basis of the NHS England's voluntary content standard¹³.

An NHS content standard should be mandatory across the NHS to provide a consistent and safe information experience for patients.

There should be "a national green light" for NHS services to signpost information certified by PIF TICK. This will avoid wasteful duplication at local level.

National NHS information should meet the robust requirements of the PIF TICK to ensure the impact of information is evaluated and co-production embedded.

Case Study

Healthinote is Cognitant's digital library of credible health information and self-management tools for people with long-term conditions. Healthcare professionals use it to create personalised information for patients. Cognitant's information is PIF TICK certified and delivered in accessible formats in multiple languages. Its Kidney Essentials programme has been used by more than 2,300 NHS patients. More than 9 in 10 reported an increase in knowledge and there was a 66% reduction in face-to-face follow-ups.

https://www.cognitant.com/healthinote-the-netflix-for-health-demonstrating-the-impact-of-personalised-information-prescriptions-on-health-outcomes/

Tackle inequality:

Health information must be accessible and appropriate for all

National governments should support development of a 'health-literacy friendly' NHS to provide everyone with health information and support. This includes:

- Updating the Accessible Information Standard¹⁴ and mandating it with the NHS content standard.
- Providing face-to-face care and printed information for those who are digitally excluded¹⁵.
- Providing translation options on key NHS products including NHS.UK and NHS apps.
- Training in information provision for healthcare professionals, providing competency across the skills mix.
- Ensuring NHS frontline staff can deliver compassionate care with cultural competence, meeting Principle 3 of NHS England's inclusion health framework¹⁶.

Case Study

HCPs working for NHS Wales are mandated by Welsh Risk Pool to use EIDO Healthcare information for surgical consent.

The PIF TICK certified library of 430 documents has accessibility options and is translated. Welsh, Arabic and Polish are the most used translations.

A quarter of a million documents were downloaded last year. The aim is to improve patient care and reduce the amount paid for claims relating to consent.

https://www.eidohealthcare.com/



Lived experience as a metric:

Embedding patient experience as a measure of performance

National measures of lived experience should be used to track progress on a range of objectives including:

- Access to information
- Being listened to
- Involved in decision making
- Treated with dignity and respect.

These feedback mechanisms should be built into the planned NHS digital ecosystem.

About Me information, meeting the standard set by the Professional Record Standards Body (PRSB) ¹⁷ should be integrated into national NHS apps and the personal health record.

This would support healthcare professionals to have better conversations with patients.

The linked PRSB standard on shared decision making¹⁸ should be implemented across the NHS.

Case Study

Nottingham and Nottinghamshire ICS has introduced About Me information on surgical pathways following a coproduction project.

As one panel member stated, "Having About Me, there is not so much of a barrier. It is a bit more equal. It does prompt the HCP to ask questions."

https://notts.icb.nhs.uk/your-health/personalised-care-2/about-me/

Dedicated leadership:

A mandate for the effective delivery of health information

NHS organisations delivering care should have a dedicated lead for health information¹⁹ mandated. They should be resourced to ensure consistent and effective delivery of information meeting national standards.

The Care Quality Commission should check the provision of information by local NHS organisations.

Population health studies should be used to assess the impact of health information.

A "do it once and share" approach should be adopted to information interventions with a positive impact on health outcomes and health inequality.

The development of a health literacy friendly NHS should be a national priority²⁰.

Case Study

Diabetes UK's learning zone offers personalised information for people with diabetes. It has 190,000 users.

9 in 10 say they are more confident to self-manage and self-care.

It has partnered with Accurx to develop text templates GPs can send to patients at diagnosis to signpost the charity's services.

https://learningzone.diabetes.org.uk/



Creating a health-literacy friendly NHS: PIF's charter for change

The PIF Health and Digital Literacy Charter asks organisations to commit to making it easier for people to navigate, understand, and use information and services to take care of their health by:

- Using clear verbal, written or digital communication.
- Creating easy-to-use digital tools, websites, printed information and premises.
- Involving users in the development of information as routine and inviting feedback.
- Training staff in health literacy.
- Considering digital exclusion and equalities impact when introducing new resources.

More than 100 organisations have signed the charter, launched in response to <u>PIF's Health</u> and <u>Digital Literacy Surveys</u>.

The PIF TICK was created to help the public quickly and easily identify trusted health information. It launched in 2020.

Today, the <u>public PIF TICK website</u> and directory feature more than 140 Trusted Information Creators.

The World Health Organization features the PIF TICK in its toolkit on tackling misinformation.

The NHS, Academy of Medical Royal Colleges (AoMRC) and YouTube Health have all used the PIF TICK criteria as the basis for their own self-assessed standards.

Academy of Medical Royal Colleges, Assuring the credibility of health information sources of social media platforms.

"We would expect that any organisation meeting the thorough requirements of the PIF TICK could easily and perhaps automatically meet these requirements.



Patient Information Forum





Appendix

Key differences across the four nations





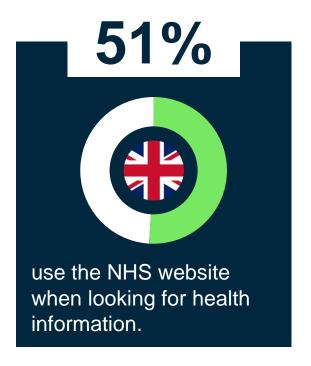


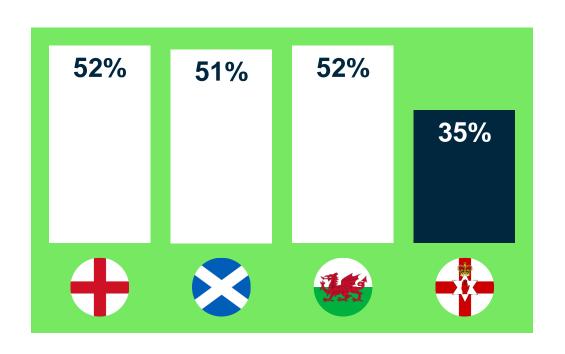




NHS websites are used to a lesser extent in Northern Ireland

Overall in the UK...



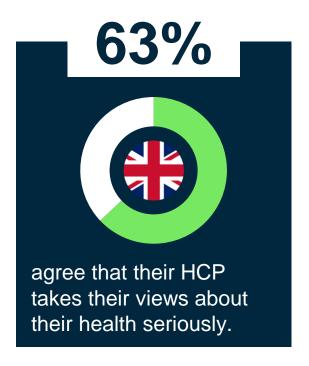


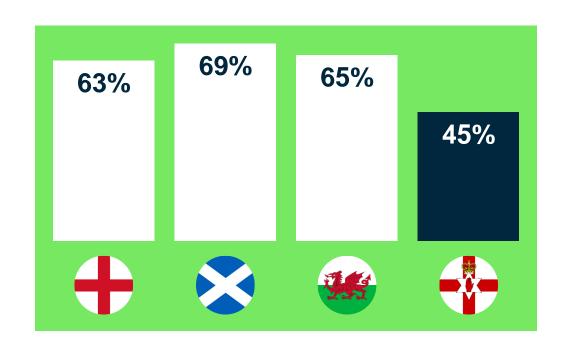
Base: All respondents (n= 2003)

Q4: When looking for health information for yourself, which of the following, if any, would you usually go to?

Agreement that HCPs take respondents' views about their health seriously is significantly lower in Northern Ireland vs. other nations

Overall in the UK...

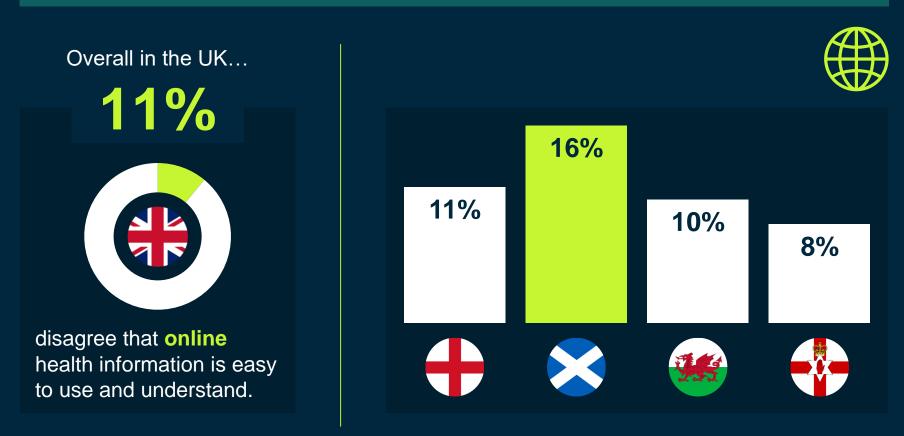




Base: All respondents (n= 2003)

Q7: For this question, please think about your health in general. To what extent do you agree or disagree with each of the following statements about your relationship with the healthcare professional you see most frequently to manage your health?

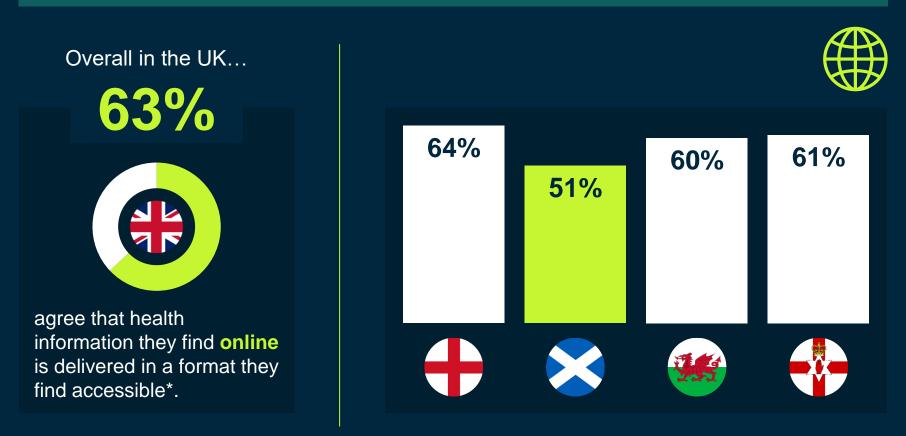
More respondents in Scotland disagree that online health information is easy to use and understand vs. other nations



Base: All respondents (n= 2003)

Q2: To what extent do you agree or disagree with each of the following statements about finding health information online?

Respondents in Scotland are slightly less likely to agree that online health information is delivered in an accessible format



Base: All respondents (n= 2003)

Q2: To what extent do you agree or disagree with each of the following statements about finding health information online?

* E.g. as Easy Reads or translated into their preferred language.

In Northern Ireland, a higher proportion of respondents say they have been personally affected by offline misinformation relating to their health vs. other nations

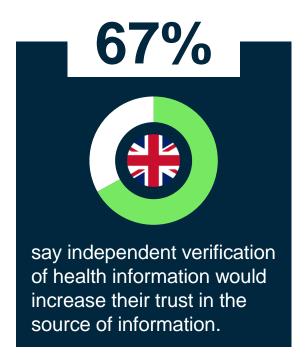


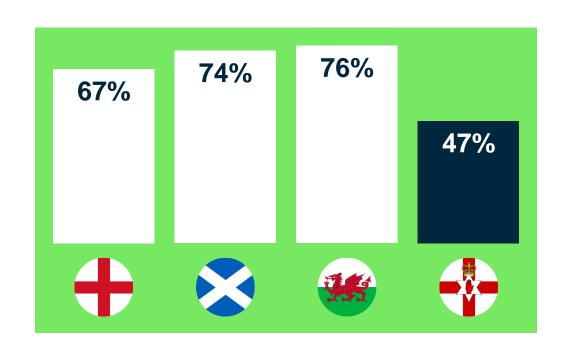
Base: All respondents (n= 2003)

Q10: To what extent do you agree or disagree with each of the following statements about health misinformation? By misinformation, we mean incorrect or misleading information, which may exist without specific malicious intent. Please think about health information you may find offline.

The independent verification of health information is less likely to increase levels of trust in the source of information in Northern Ireland vs. other nations

Overall in the UK...





Base: All respondents (n= 2003)

Q13: To what extent, if at all, would the independent verification of health information increase or decrease your trust in a source of information?





Technical Notes



Technical note

Recruitment to the panel

Panelists are recruited via a random probability unclustered address-based sampling method. This means that every household in the UK has a known chance of being selected to join the panel. Letters are sent to selected addresses in the UK (using the Postcode Address File) inviting them to become members of the panel. Invited members are able to sign up to the panel by completing a short online questionnaire or by returning a paper form. Up to 3 members of the household are able to sign up to the panel. Members of the public who are digitally excluded are able to register to the KnowledgePanel either by post or by telephone, and are given a tablet, an email address, and basic internet access which allows them to complete surveys online.

Conducting the survey

The survey was designed using a 'mobile-first' approach, which took into consideration the look, feel and usability of a questionnaire on a mobile device. This included: a thorough review of the questionnaire length to ensure it would not over burden respondents from focusing on a small screen for a lengthy period, avoiding the use of grid style questions (instead using question loops which are more mobile friendly), and making questions 'finger-friendly' so they're easy to respond to. The questionnaire was also compatible with screen reader software to help those requiring further accessibility.

This study was conducted on the KnowledgePanel between 30 May – 5 June 2024.

Weighting

In order to ensure the survey results are as representative of the population as possible, the below weighting spec was applied to the data in line with the population profile.

Up to three people per household were allowed to complete this survey. To account for this and varying household sizes, we employed a design weight to correct for unequal probabilities of selection of household members.

Calibration weights have also been applied using the latest population statistics relevant to the surveyed population to correct for imbalances in the achieved sample. England and Wales, Scotland, and Northern Ireland were weighted together, while an additional weight has been created for the United Kingdom to account for any over or under sampling within each of these countries.

The calibration weights were applied in two stages:

- The first set of variables were an interlocked variable of Gender by Age (using ONS 2022 mid-year estimates as targets), and region (using ONS 2022 mid-year population estimates).
- The second set were Indices of Multiple Deprivation (quintiles) (ONS mid-year estimates 2019) Education (Annual Population Survey 2018), Ethnicity (APS October 2022 – September 2023) and number of adults in the household (ONS census 2021 for England, Wales, Northern Ireland, and 2021 mid-year estimates for Scotland).

Weighting profile targets

AGE & GENDER				
	Male	Female	In another way	PNTS
18-24	5.3%	5.1%	0.2%	0.1%
25-34	8.1%	8.5%	0.2%	0.1%
35-44	7.9%	8.4%	0.2%	0.1%
45-54	7.9%	8.2%	0.1%	0.0%
55-64	7.9%	8.2%	0.0%	0.2%
65-74	5.9%	6.3%	0.0%	0.1%
75+	4.9%	6.4%	0.0%	0.0%

REGION		
North East	4.0%	
North West	11.1%	
Yorkshire and the Humber	8.2%	
East Midlands	7.3%	
West Midlands	8.8%	
East Of England	9.4%	
London	13.0%	
South East	13.8%	
South West	8.7%	
Wales	4.7%	
Scotland	8.3%	
Northern Ireland	2.8%	

ETHNICITY		
White	84.9%	
Ethnic Minorities	13.8%	
Don't know / Prefer not to say	1.4%	

IMD QUINTILES				
1	20.0%			
2	20.0%			
3	20.0%			
4	20.0%			
5	20.0%			

EDUCATION			
Degree level or above	30.3%		
Below degree level	68.4%		
Prefer not to say / Not stated	1.3%		

NUMBER OF ADULTS IN THE HOUSEHOLD		
One adult	21.2%	
Two or more adults	78.8%	

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The Patient Information Forum (PIF) is the independent membership body for people working in health information and support. We are the independent voice of UK health information. PIF runs the only quality mark for print and digital information – the PIF TICK. PIF has promoted access to trusted health information for patients, carers, the public, and healthcare professionals for more than 25 years. Extending our influence and impact is only possible with the support of our members and the partnerships we build with like-minded organisations. Our vision is for everyone to have access to personalised health information and to enable them to make informed decisions about their health, wellbeing and care.