Health information needs of patients and caregivers

A survey overview

In 2018, the PM Society Patient Engagement Interest Group created a survey designed to assess the health information needs of patients, caregivers, relatives and friends.

Questions asked were designed to explore:

- What health information people need and when they need it
- Where and how they find health information
- What information is useful and what is not
- What information is missing or is difficult to find
- Preferences in terms of the format that health information is presented in

510 completed surveys

Two survey collectors were created – one to generate insights from talk**health** members, and the other to gather insights from the wider population through a collector distributed by PM Society members. 333 and 234 people responded via talk**health** and the PM Society respectively. This fact sheet provides an overview of some of the key findings from the survey.
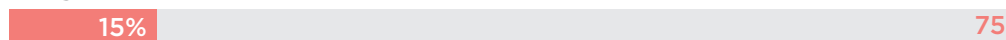
333 people responded via talk**health**

234 from the PM Society distribution
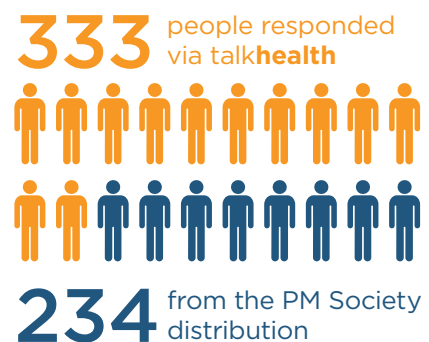
In what capacity are people looking for health information?

Results have been rounded to the nearest full number

Patients
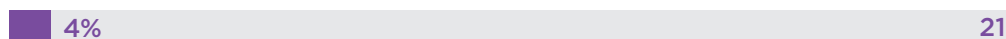| 71% | 363 |

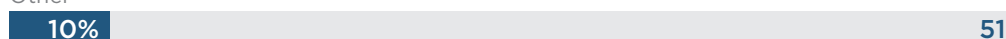Caregiver/relative
| 15% | 75 |

Friend
| 4% | 21 |

Other*
| 10% | 51 |

* Includes nurses, doctors, homeopaths for patients, health workers and support workers

Demographics

Age of participants

16-24 years **5%**
25-34 years **21%**
35-44 years **22%**
45-54 years **24%**
55-64 years **17%**
over 65 years **10%**
prefer not to say **1%**

Gender

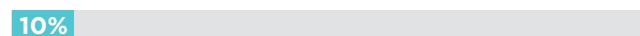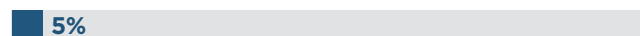15% Male

84% Female
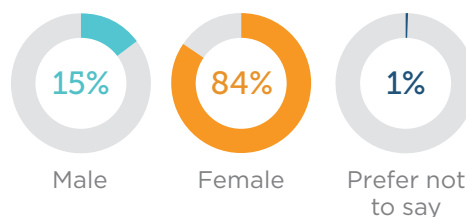
1% Prefer not to say

Ethnicity

White (English/Scottish/Welsh/Northern Irish/British)
79%
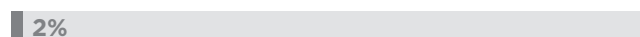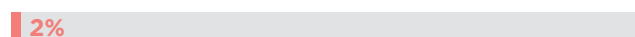
White (any other white background)
10%

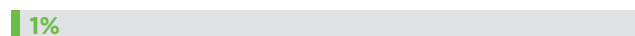Asian/Asian British (Indian/Pakistani/Bangladeshi/Chinese/any other Asian background
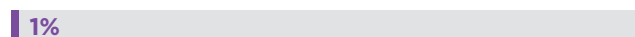**5%**

Prefer not to say
2%

Black/African/Caribbean/Black British
2%

Mixed/multiple ethnic groups/other (please specify)
1%

White (Irish)
1%

Region of the UK participants live

Geographically, respondents were spread across the UK, with the following areas being the top four regions:

- England: North West: 18%
- England: South East: 18%
- England London: 15%
- England South West: 9%

Level of education

34% Degree

18% Post-graduate degree

17% GCSEs/O Levels/CSEs

14% Diploma

12% AS/A Level

3% Other (please specify)

2% Prefer not to say

Note: Results have been rounded to the nearest whole number throughout this document.
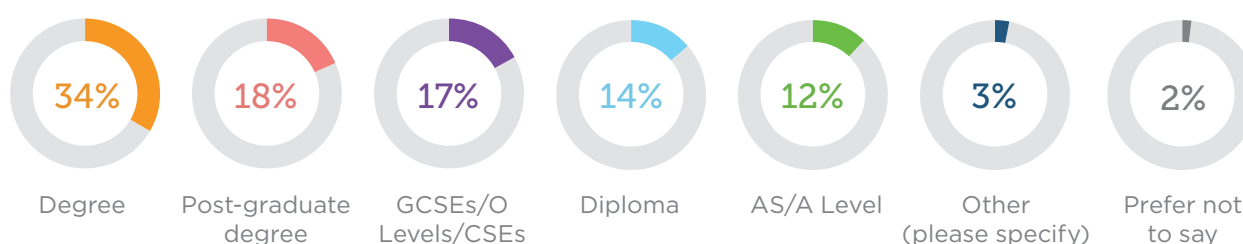
# How often do patients use technology in their day-to-day life and to access health information?

In day-to-day life (eg the internet, social media, work, communication, hobbies etc)

A large majority of respondents used technology in their day-to-day life (98%), with 1% using technology only weekly.

We asked respondents how frequently they use technology specifically to access health information and the results were quite different:

Frequency of technology use to access health information

- 1%
- 21%
- 11%
- 28%
- 39%

- Daily
- Weekly
- Monthly
- Rarely
- Never
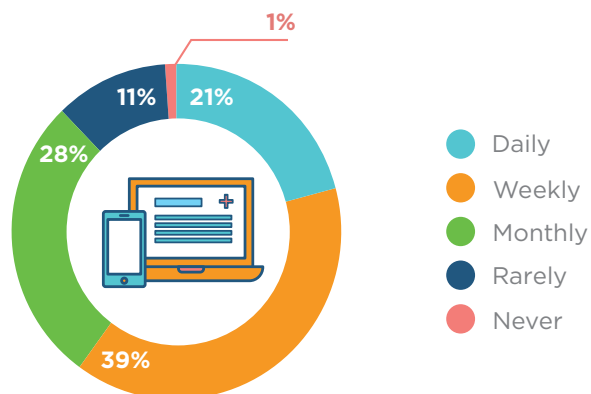
What is the primary reason patients look for health information?

The reasons for looking for health information

Symptoms – you look to find the cause of the patient's symptoms (e.g.headache, pain, stomach cramp etc)

78%

Treatment – the patient has been prescribed a specific medicine or treatment by a healthcare professional

64%

Diagnosis – the patient has received a diagnosis (e.g. long-term condition, such as cancer, or short-term condition, such as tonsillitis)

60%

Lifestyle – the patient needs to manage a long or short-term condition with lifestyle changes (e.g. nutrition, exercise, smoking cessation)

52%

Condition Management – the patient has a chronic long-term condition (such as diabetes)

51%

Procedure or tests – the patient is undergoing a procedure or tests (e.g. blood tests, scan etc)
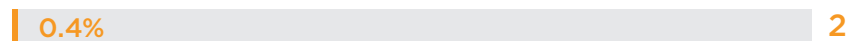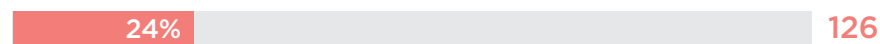
45%

Other (please specify)

5%

In the results above, more than one option could be selected, and answers could be on behalf of the patient or on someone else's behalf

How well the information answers the questions when accessing health information
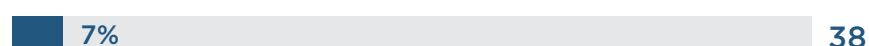
Not at all

| 0.4% | | 2 |

A little

| 24% | | 126 |

A lot

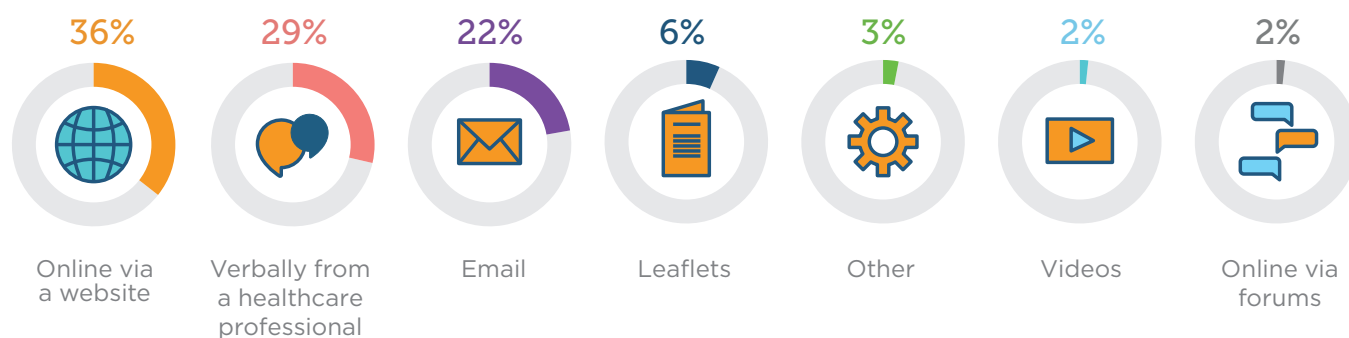| 68% | | 344 |

It answers all of your questions

| 7% | | 38 |

Other information people would like to have

Patient stories and local support

Lay summaries of recent research | Access to experts on-demand

- Information on local support groups specific to my health conditions. For myself and family members to access.

- Disease summaries and treatment options in easy to understand language for patients

- Information on local support groups specific to my health conditions. For myself and family to access.

- More information from fellow sufferers.

- Online access to a nurse who could answer questions when I can not get hold of my district nurse

How do patients prefer to receive health information?

36%	29%	22%	6%	3%	2%	2%
Online via a website	Verbally from a healthcare professional	Email	Leaflets	Other	Videos	Online via forums

- **Online via a website:** It's easily accessible: it can be accessed anywhere and you can't lose the information

- **Verbally from an HCP:** Chance to ask questions and discuss, tailored to me as the patient

What were the general views on other health information received, or information that is found to be particularly good or bad?

Helpful

- NHS
- WebMD
- Facebook groups
- Charity websites
- talk**health**

> www.webm.com I find this is an excellent site for looking up health information especially drugs and supplements my patients are using.

> I like the NHS website, clear and we'll laid out. But very pharmacy/drug driven. Often alternative medicine should be explored.

> Charity website are usually excellent.

Unhelpful

- Newspaper articles
- Chat forums
- Conflicting or confusing advice from HCPs
- Information overload
- Lack of F2F time with HCPs

> Articles in the news and the daily mail are really troublesome, they spread A LOT of misinformation.

> Chat forums on other websites can also be either helpful on more worrying.

> Information I find unhelpful is mainly from Doctors who all give you different information and totally confuse you.

In conclusion, what did patients say they want?

More time with their doctor

Trusted information

Non-conflicting information

The patient survey was hosted on the talk**health** community platform, with people from both the talk**health** community and the wider population completing the survey and providing their feedback and views.

Look out for subsequent fact sheets produced by the PM Society Patient Engagement Interest Group. These will cover specific insights around the similarities and differences between the two datasets, a best practice guide on patient preferences for health information, most and least useful sources of information, and health literacy themes – for example, how does education and socio-economic background impact the understanding of health information?

If you would like to find out more, please go to:
https://pmsociety.org.uk/category/patient-engagement.