

# Health information needs of patients and caregivers

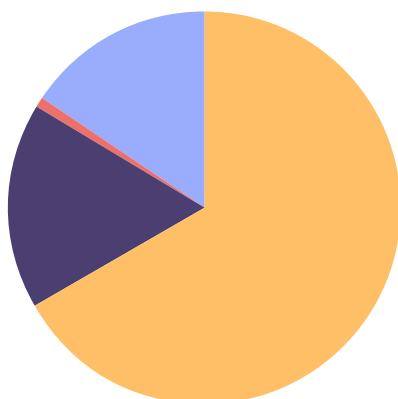
In a PM Society's Patient Engagement Interest Group (PEIG) survey carried out in 2018, interesting insights into patient preferences for health information were revealed. Across a series of factsheets, we explored what patients want from health information, how and where they access it and how that differs based on their education level. In this fourth factsheet in the series, we compare the two datasets to highlight the similarities and differences between the results from the two data collectors.

## Dataset collectors



**PM Society collector** - includes over 230 UK companies as members, online survey link shared by members of the PEIG.

196 responses

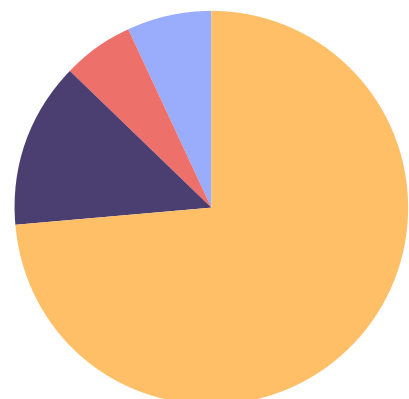


67% ● Patient  
17% ● Caregiver/relative  
1% ● Friend  
15% ● Other



**talkhealth platform** - one of the UK's leading online social health communities.

314 responses

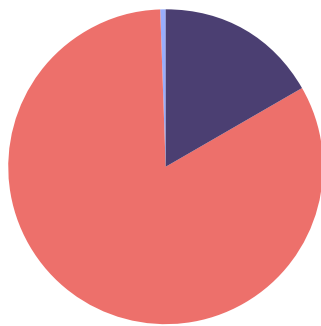


74% ● Patient  
13% ● Caregiver/relative  
6% ● Friend  
6% ● Other

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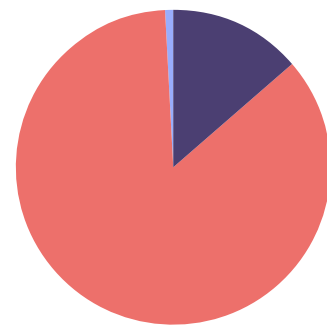
## TALKHEALTH

## Demographics of the two datasets



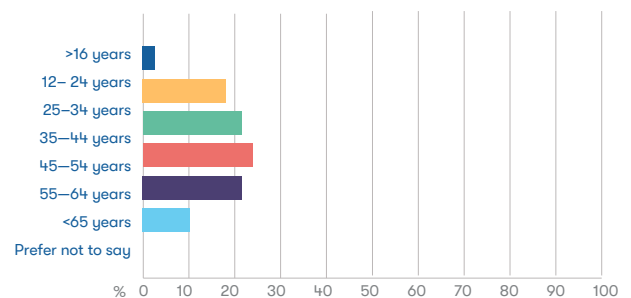
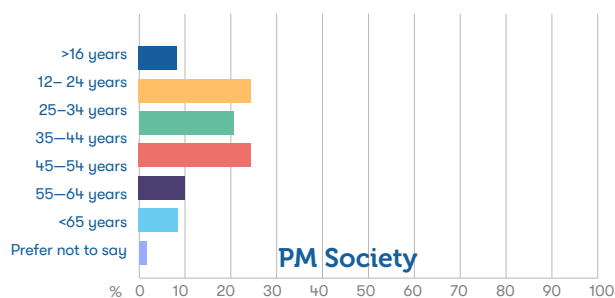
## Gender

**16%** ● Male  
**82%** ● Female  
**1%** ● Prefer not to say

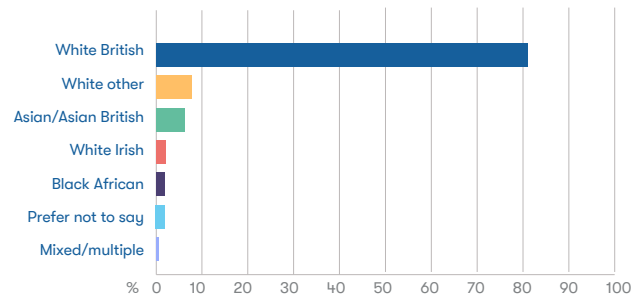
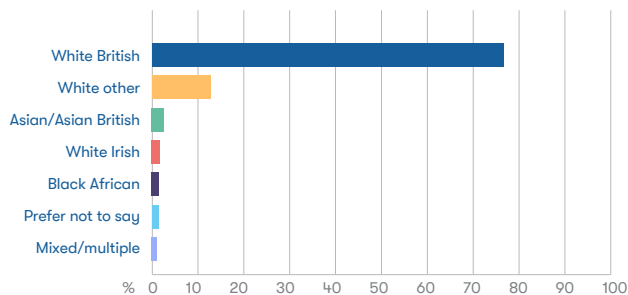


**14%** ● Male  
**85%** ● Female  
**1%** ● Prefer not to say

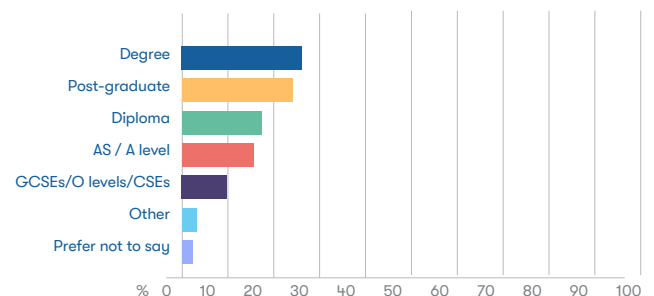
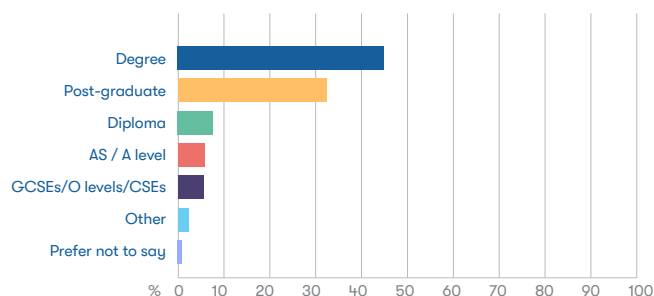
## Age



## Ethnicity



## Education



### Key findings

- › In both collectors, **patients** were the highest percentage of respondents (74%\* for talkhealth, 67%\* for the PM Society) followed by a similar contribution from caregivers (an average of 15% in both collectors).
- › **Female** respondents were the highest percentage in both datasets (over 80%) with an average age range between 25-64 years.
- › **White English** was the most represented ethnicity in both collectors (over 75%)

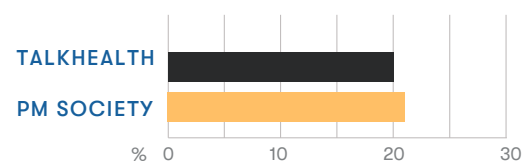
although the PM Society collector contributed a more heterogeneous white background other than English.

- › Education level was **higher** in the respondents from the PM society collector (degree or a post-graduate degree made up 45%\* and 32%\* respectively) while respondents from the talkhealth platform showed an equal distribution between degree (26%\*) or special degree qualifications (24%\* for GCSEs, O levels or CSEs) with less than 10% respondents with a post-graduate degree.

### Use of technology was largely similar

#### Key findings

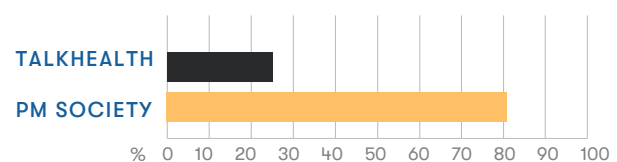
- › In day-to-day life, technology was used in both datasets on a daily basis with **approximately 20%** of respondents using technology on a **daily basis** to access health information.



### Close friends or relatives who work in the healthcare sector showed a relevant difference

#### Key findings

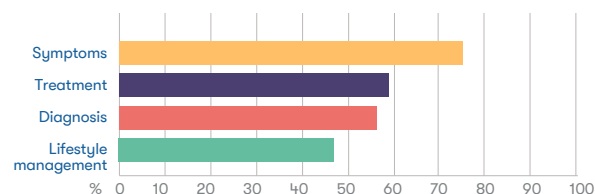
- › A relevant difference between the two datasets was highlighted by the percentage of close relatives or friends who work in the healthcare sector: **over 80% for the PM Society** collector compared with **25% for talkhealth** platform respondents



However, in both collectors, around 50% of respondents stated that knowing this person did not impact their knowledge or ability to access health information; the other half considered this impactful.

## Why patients look for healthcare information?

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### Key findings

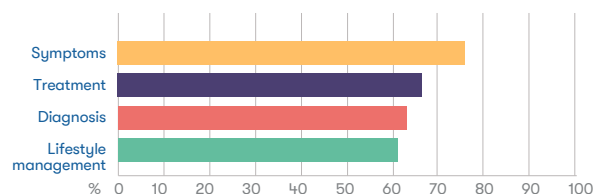
- › **Symptoms** were the primary reason why respondents look up for health information, followed by treatment and diagnosis in both datasets. The fourth most common reason differed between the two datasets, with talkhealth respondents citing condition management and PM Society respondents citing lifestyle.

## Support from other patients/online forums:

”

We can ask questions and share concerns

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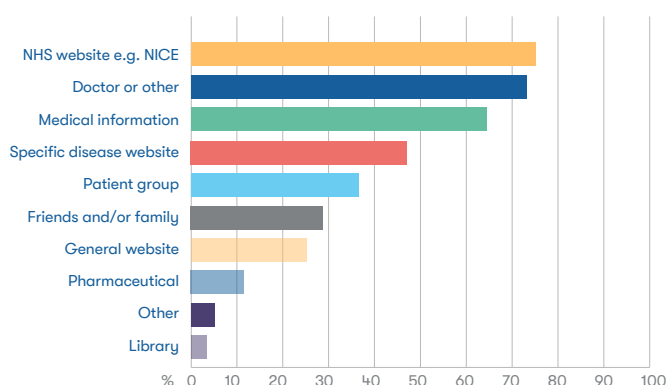


### Other reasons mentioned by respondents to look for health information included:

- › Data from clinical trials
- › Information about prescribed drugs
- › Learning about their condition and its impact (in the PM Society collector)
- › Support from other patients with the same condition, information on drug reactions and alternative medicine were additional reasons mentioned in the talkhealth collector

## Most trusted sources of healthcare information

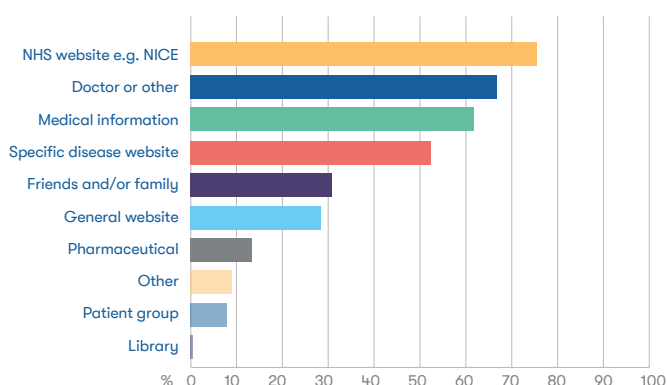
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### Key findings

- › NHS websites (including NICE guidelines, NHS direct and NHS choices) were the most trusted sources of health information identified by both collectors (around **75% of preferences**).

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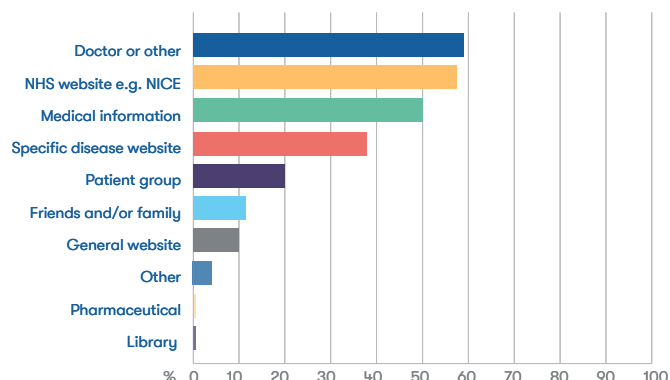
- › Both collectors reported that **doctors or other healthcare professionals** (e.g. nurses and pharmacists) are other trusted sources of health information (**over 66%** of answers) followed by **medical information websites** such as WebMD or patient.co.uk (**over 60%** of preferences in both collectors).

1. **NHS websites** (including NICE guidelines, NHS direct and NHS choices)
2. **Doctors or other healthcare professionals**
3. **Medical information websites**

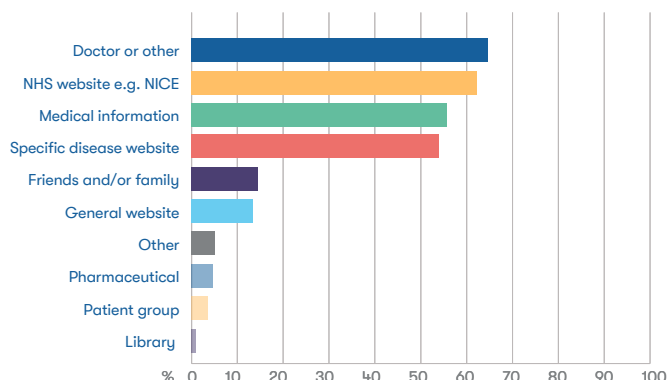
Less than 15% of respondents in both datasets chose pharmaceutical or healthcare company websites as sources of trusted health information.

### Most useful sources of healthcare information

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TALKHEALTH



### Key findings

› There was a similar trend concerning the most useful sources of information: **doctors or other healthcare professionals** were identified as the most useful source (58%\* of talkhealth answers and 63%\* of PM Society's dataset) followed sequentially by NHS websites, medical information websites, and

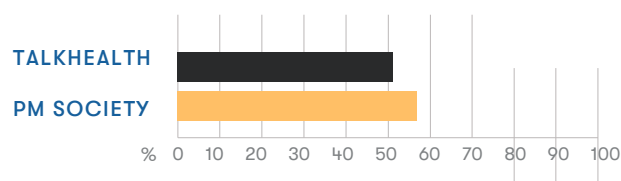
specific disease websites (e.g. Cancer Research UK or Macmillan). General websites like Wikipedia were cited as the least useful sources of health information (44%\* of talkhealth collector and 51%\* of PM Society dataset) followed by library or friends and/or family in both collectors

About one third of respondents in both datasets reported pharmaceutical or healthcare company websites as the least useful source

### Is the information pitched at the right level?

#### Key findings

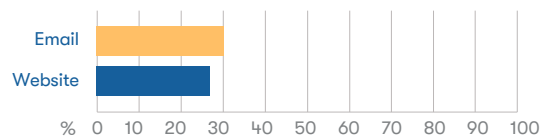
› In both collectors, about half of the respondents considered the complexity of the information **at the right level** (51%\* of talkhealth respondents, 57%\* in the PM Society's dataset).



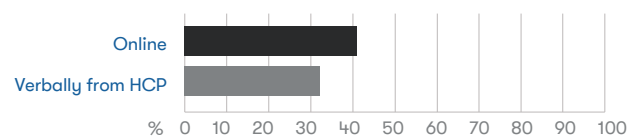
A very low percentage of users (2%) considered the information too complicated to have value - which may not be representative of the general population.

## How to receive health information

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One third of respondents of the talkhealth platform would prefer to receive healthcare information by **e-mail or online via a website** (30%\* and 27%\*, respectively) while PM Society's respondents prefer to receive information **online** (41%\*) or **verbally from a healthcare professional** (32%\*). Leaflets were chosen by 9%\* of talkhealth respondents and 4%\* of PM Society's users

Online  
via website

”

Available 24-7,  
Usually up-to-date,  
More personal

Via  
email

”

Because it's  
personal to me

## Summary

### Similarities in the datasets

- › Overall, despite the limitations due to a specific demographic group (white female respondents), the two collectors expressed similar trends concerning
- › The reasons to look up for information
- › The trusted sources of information
- › The least useful sources of information

### Differences in the datasets

- › The number of responses
- › Education
- › Friends or relatives in the healthcare sector

Respondents of both collectors stressed on the need to receive:

- › Clear information, in patient appropriate language
- › Professional support by phone
- › Availability of clinical trial results
- › Prevalence and prognosis of their specific disease

\*Percentages have been rounded to the nearest whole number.