Covid Choices Main Findings 2020

I want to go to my hospital appointment... what about Covid?

Patient
Information
Forum

Introduction

The Covid Choices survey was led by PIF and developed by a collaborative group which included patients with long term condition and other partners:

Sue Farrington, Chair, Patient Information Forum and Chief Executive, Scleroderma & Raynaud's UK.
Sophie Randall, Head of Strategy and Partnerships, Patient Information Forum.
Ben Afia, Language Strategist, Afia.com.
Trishna Bharadia, Expert Patient and Patient Engagement Consultant.
Liz Clark, Vice President, Medical Affairs, Norgine.
Alan Clarke, Expert Patient, Bowel Cancer.
Dan Berry, Behavioural Science Unit, Hill & Knowlton Strategies.
Dr Alex Freeman, Executive Director, Winton Centre for Evidence and Risk Communication.
Anisha Gangotra, Expert Patient.
Ceinwen Giles, Shine Cancer Support. Chair of Patient & Public Voices Forum, NHS England Cancer Programme.
Jane Leahy, Expert Patient, Blood Cancer.
Rachel Power, Chief Executive, Patients Association.
Emma Sutcliffe, NexGen Healthcare Communications.
Seb Tucknott, CEO, IBD Relief.
Penny Ward, Consultant Pharmaceutical Physician with special interest in COVID-19.

PIF would like to thank Norgine UK for providing partial financial support for the survey.

We would also like to thank Hill+Knowlton Strategies, NexGen Healthcare Communications and Ben Afia for providing pro bono support. PIF would also like to thank Rosa Maryon for her work on the Qualitative Analysis.

COVID-19 and patient information

This has been a challenging time for all: for key workers on the front line; for scientists and academics doing their best to understand the impact of COVID-19, for our members providing up-to-date patient information and for the public struggling to get to grips with what this means for their daily lives.

COVID-19 has highlighted the importance of clear messaging, which is culturally appropriate and speaks directly to everyone to help reduce fear and anxiety. Ensuring information is inclusive and does not reinforce health inequalities is essential.

As we enter winter, we must learn from the last six months and ensure people have access to clear, consistent information, so they can be confident about protecting themselves and accessing the care they need.

Sue Farrington – Chair, PIF

Contents

Executive summary

Background

Information to help people make the right decisions about their general health and treatment against perceived risk of COVID-19 infection has been a key concern of PIF members throughout the pandemic.

The Covid Choices survey was developed with a collaborative group of expert patients and other partners (see previous page) with partial funding from Norgine Ltd.

The survey was hosted on Survey Monkey with the link distributed on social media and by patient networks and groups. It ran for 2 weeks at the end of July, just as shielding ended and lockdown restrictions were easing.

More than 800 people responded to the survey and made more than 1000 detailed free text comments expressing their concerns.

The vast majority of people had a health condition or cared for someone who did. Around 60% said their long-term condition put them at risk of infection and just under half were shielding. Responses represented people with a wide range of health conditions.

Key findings

Fear of catching and becoming seriously ill with COVID-19 outweighed concerns about respondents' existing health conditions.

Around 1 in 3 people said they had delayed healthcare and this was broadly consistent across all conditions. This rose to 2 in 5 for people with diabetes, lung disease and mental health conditions.

People had switched to home therapy, delayed starting new treatments, avoided routine medication monitoring or self- managed. Some felt their health had deteriorated while they waited for the pandemic to abate.

> ***'Lack of information before appointments causes concern. It is stopping some people getting the care they need. Concern about future appointments could be reduced with better information from Trusts and GPs about COVID-19 safety measures in place. This is vital as the NHS moves to phase 3 and resumes a more normal service.'***
>
> Sue Farrington – Chair, PIF

1 in 3

delayed healthcare or treatment

Lack of trustworthy information and information conflicts

A lack of trustworthy information and conflicting guidance emerged as key concerns and barriers to seeking medical help.

Almost 80% of people trusted information supplied by the NHS. Fewer than half of respondents (45%) trusted information from the UK government.

Trust had been undermined by conflicting information particularly in relation to masks and shielding advice.

When asked how they preferred to make decisions 68% said they preferred to follow trustworthy guidance.

However, 75% of respondents described information on COVID-19 as conflicting to some degree, leaving people to come to their own decisions. This confusion may present particular challenges for people with low health literacy, perpetuating health inequality.

A sub-analysis of the data found the main factor driving concern was whether people had access to trustworthy information. This was bigger than any other demographic factor or underlying condition.

The areas where people felt information was most lacking was accurate data on risk locally and on their own personal risk of COVID-19 related to their condition and treatment.

> ***'The need is clear for personalised, trustworthy information on COVID-19 risks, safety protocols in place and how to cope with this pandemic. This is crucial to the health of patients with long-term conditions as we adjust to the new normal. We need a collaborative approach to ensure that patients feel secure and informed, particularly in the case of local lockdowns.'***
>
> Trishna Bharadia
> – Patient Advocate

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

Getting people back to care

Of the 70% who had attended care, one in four did not have prior information on safety measures in place. But most (61%) were satisfied with precautions in place.

57% of people had concerns about attending future face to face care. As cases rise this concern may increase, particularly for those who lack information, have been shielding or perceive themselves to be at risk.

The results identify a real need for the NHS to go beyond telling people to attend hospital and GP services and to place an emphasis on explaining how the NHS is working to keep them safe throughout their healthcare experience.

People want clear practical information about COVID-19 secure measures in their local hospital and GP practices. This can help overcome the uncertainty that may stop people attending (see page 13).

Analysis the of free text comments found simple clear instructions about appointments would help ease anxiety.

Patients wanted to know

- Where they would be seen.
- Whether they would be seen face to face, and could bring a carer.
- How they would access facilities upon arrival.
- What doctors and nurses would be wearing.
- Whether they should wear a face mask.
- How they would be kept safe from the threat of the virus.

Patients also wanted clear advice on the services available to them, what to expect from changes to care and choice of remote or in person consultation.

57% are concerned about risk from future face to face care

> ***'COVID-19 safety needs to become part and parcel of every appointment. Patients shouldn't need to ask. Information should be given at the time an appointment is booked, with clear advice about what precautions are being taken at the medical centre and what precautions the patients themselves should take before and during attendance.'***

Ceinwen Giles
– Shine Cancer Support

Recommendations

- NHS Trusts and GP surgeries to provide clear, practical advice to patients on COVID-19 security measures in place before appointments to encourage people to return to care.
- Consistent advice across NHS services for people with long term conditions on COVID-19 risk related to their condition and treatment in consultation with national charities.
- Choice for people with long term conditions on how care is delivered, remotely or in person, so they can make a decision related to their immediate health needs, their personal risk factors and COVID-19 security measures in place.
- The provision of/or signposting to translated information and information in accessible formats.

Case study: Providing a consistent message for people with MS

The Information Teams at MS Trust and MS Society have been working together since the outbreak of COVID-19 to ensure their users receive the best information possible. Claire Winchester, Head of Information and Engagement at the MS Trust explains how the collaboration worked.

We did work quite carefully with the MS Society to ensure that we were putting out the same message, particularly at the early stages of lockdown, and in terms of how we communicated about shielding and the risks to people with MS on different disease modifying drugs.

We kept in close contact with Phil Anderson at the Society, and conferred on wording and interpretations before updating our own websites and communications channels.

We were both taking our lead from guidance by the Association of British Neurologists, interpreting the UK Government information as it applied to people with MS, and aiming to minimise conflicting advice. By working together in this way, we were able to get a sense check of our own interpretations, and avoid having to discuss each others' approaches within the MS community, being confident that our messaging matched.

On the down side, at a time at which we were all experiencing capacity pressure, extra time and effort was needed to maintain this link. Working with any partner organisation does tend to impose an additional timeline on the creation of content and communications. I'm nonetheless really glad that we both prioritised this collaboration, as it very likely saved us more work in the longer term, and gave the MS community the very best service.

Encouraging people back to care

Case study: Guy's and St Thomas' NHS Foundation Trust

The Information Team at Guy's and St Thomas' NHS Foundation Trust has been busy supporting the hospitals' clinics and services to get information out to patients. Patient Information Manager, Nicki Bickford, describes how the team has risen to the challenge.

Services and clinics are evolving and changing the way they interact with their patients in person, remotely, in the community, and at home. We are inundated with enquiries on how best to communicate with patients, so our service is evolving too.

A triage system was set up to respond to demand. The patient information lead, general manager and clinical lead from the directorate review, assess, sign off and prioritise each application before submitting to us.

Materials for patients and the public

Website constantly reviewed and updated – Our digital team has created a coronavirus page with up-to-date information and all service/clinic pages are regularly reviewed and updated to reflect changes in national guidance and the way that services are being organised to meet the needs of patients and visitors.

A generic film for all patients about keeping them safe – The home page film shows how patients will be expected to wear a mask (unless they are exempt) and the signage in place encouraging them to keep apart.

Public films in production to encourage a return to care – coming in for cataract surgery, coming in for diabetic eye screening, paediatric urotherapy.

Service specific films – These show patients how to do something at home rather than come into hospital for an appointment. These are sent as private links to the patient group. Examples include cleaning your PICC line, applying a heart monitor, MSK physiotherapy exercise programme, urology injections.

Webinars – These have replaced workshops and include a pre-recorded talk followed by a live Q&A.

Podcasts – Patients talking to clinicians about their experience, concerns, benefits, one for patients on a weight loss programme.

The team has changed the way it works while coping with the huge surge in demand. The changes have revealed new challenges. These include an increased volume of enquiries, managing expectations, keeping up with the tech, expanding our range of services and the governance of new channels and platforms.

Guy's and St Thomas' NHS Foundation Trust holds the PIF TICK quality mark for trustworthy patient information.

Trusted Information Creator

Harness behavioural insights to reassure patients

Applying behavioural insights to patient information may help reassure people when it is safe to attend. Dan Berry, Behavioural Science Unit, Hill+Knowlton Strategies provides a six-point guide.

The Covid Choices survey found that lack of trustworthy information is associated with concern about contracting COVID-19. Providing clear and consistent information can help overcome this, harnessing behavioural insights can help address people's fear.

Attitudes: What are the risks and benefits?

- Patients have a lot of pros and cons to weigh. Some risks are more apparent than others, so patients may give those more attention than to benefits that less readily come to mind. Each clinic should communicate its own specific risks and benefits. The best way to communicate clearly is to use case studies or whole numbers – rather than percentages. For example, 'last year we detected early stage cancer in 350 patients, who went on to be treated successfully', so it is easy for the patient to grasp the benefits.

Trust: The experience and values of procedures from a patient's viewpoint.

- The perceived source of a message can matter as much as the content of the message itself. If patients attend a clinic frequently and get to know their doctor or nurse, those professionals are trusted and respected messengers. Creating a perception that a request to attend an appointment is from a doctor or nurse rather than an anonymous 'from the hospital' message can boost trust.
- Conceding a small problem adds to the authenticity of the overall message. In communications, concede a blemish such as 'while the waiting room isn't as comfortable as it was, we've done this to keep you safe'.
- We tend to go with the flow of what most other people do, or what we perceive they do. A problem with COVID-19 is that people may perceive group objections or concerns that are no longer the case – such as people not attending clinics.

> ***In communications, concede a blemish such as 'while the waiting room isn't as comfortable as it was, we've done this to keep you safe'.***

Communicate a positive social norm, such as 'our clinics are getting back to normal and patients are coming back in again' rather than 'sadly loads of our patients are cancelling' which is a negative norm.

> ***Communicate a positive social norm, such as 'our clinics are getting back to normal and patients are coming back in again'.***

Reduce uncertainty: Demystify the process and give concrete steps

- Most of us dislike uncertainty. Patients may not know where they can sit to wait for their clinic or how to get through the hospital site. Do all you can to minimise that uncertainty. For example, share photographs of what the waiting room now looks like, or of the route from the entrance to the clinic.
- Many patients may be initially persuaded to attend appointments, for example when having a phone consultation with a nurse, but then subsequently not do so. One way to narrow this gap between someone's good intentions and their actions not following through is by asking the patient to make a pledge. There is some evidence that even stating out loud a pledge to attend can be effective.

Below are some other behavioural recommendations to help increase patient confidence.

Reciprocity: Most patients care about the NHS and want to do their bit to protect it. Communicate that, right now, they can do their bit by attending their clinics.

Attention: We are all bombarded with more information than we can possibly consciously process. A typical NHS clinic may be plastered wall-to-wall with signage. While this is well-intentioned it may risk the crucial COVID-19 information not being noticed as much as desired. Likewise, outpatient letters commonly run to multiple pages. Less is more: what can the clinic cut of it's other messaging – at least temporarily – so COVID-19 messages are noticed?

Understand 'the real why': Spend time thinking of some hidden barriers. These are things that matter to real people in the real world, but which may not be said in a survey. For example, maybe a patient likes attending their diabetes clinic because they chat with people in the waiting room and swap gossip with the receptionist. If that social connection is no longer possible due to social distancing, this might be the reason for non-attendance – even if the patient is unlikely to consciously state this.

The Behavioural Science Unit, Hill+Knowlton Strategies, provided pro bono sub analysis to the Covid Choices survey.

Main Findings

Representation

Biggest groupings

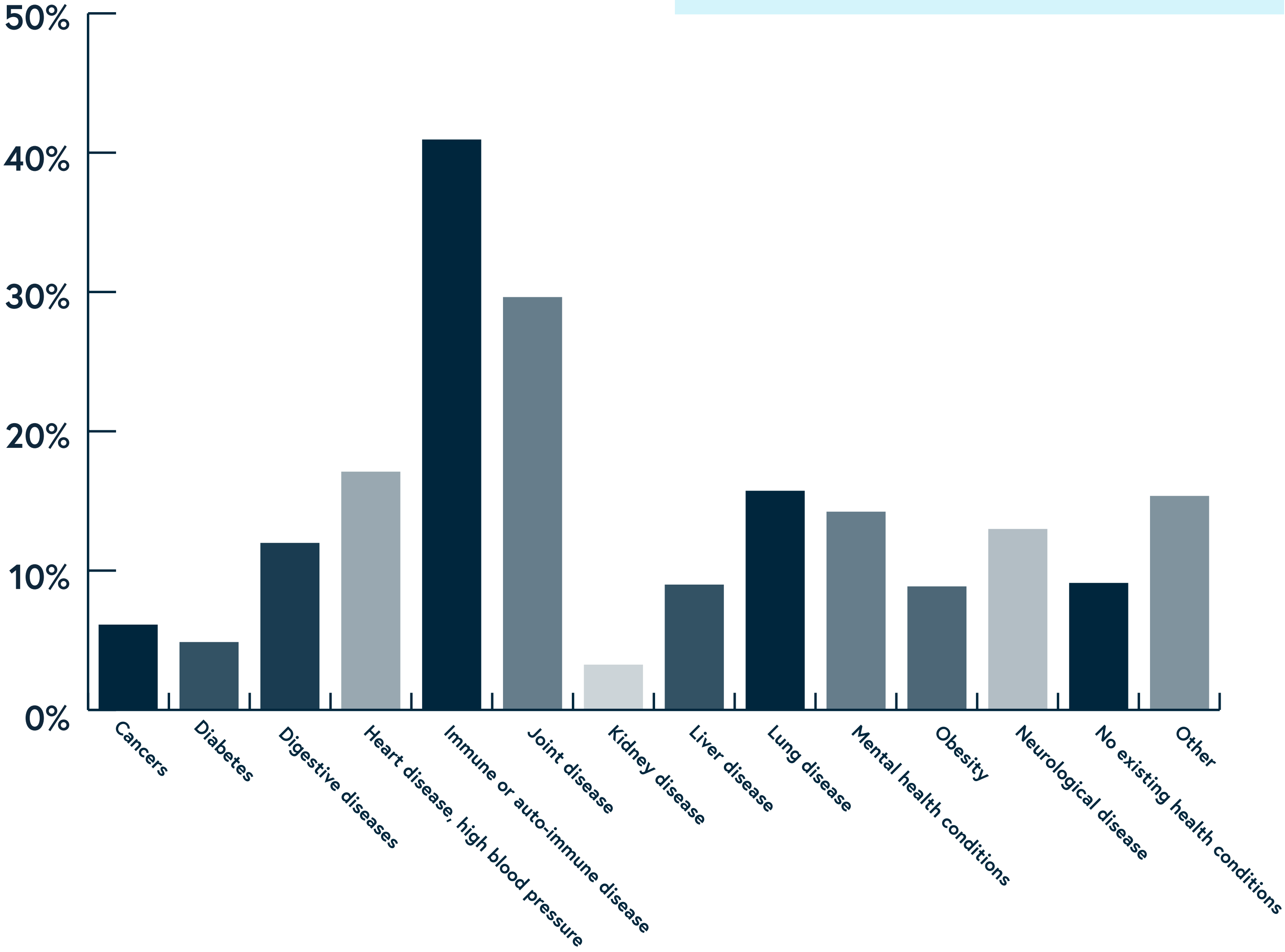
- Immune/auto immune conditions – 41%
- Joint disease – 30%
- Heart disease – 17%
- Lung disease – 16%
- Mental health – 15%
- Neuro – 13%
- Digestive – 12%

Only 13% had no existing health conditions.

Age brackets

Most respondents were working age adults. 90% were women, suggesting a role of 'Chief Medical Officer of the family'.

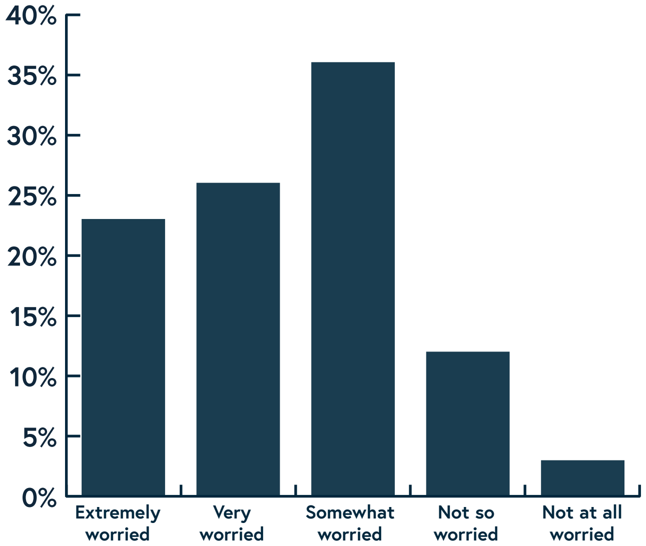
- Under 25 – 2%
- 23-44 – 22%
- 45-64 – 54%
- 65-74 – 18%
- 75–84 – 4%
- 85+ – 0.4%



Concerns

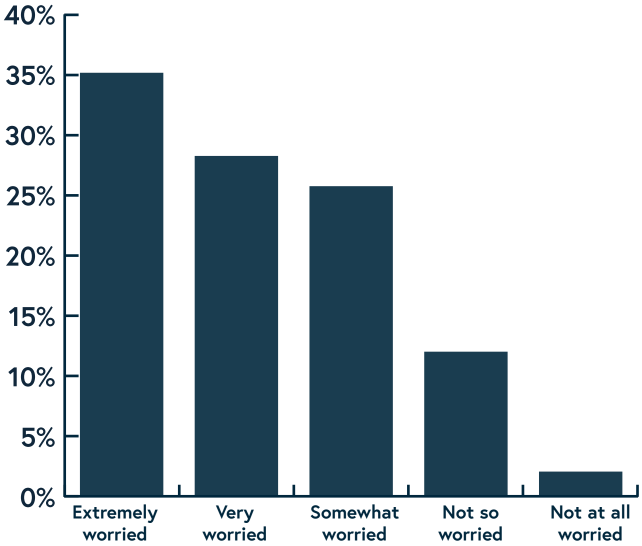
Catching COVID-19

- 48% extremely or very worried
- 37% somewhat worried



Becoming seriously ill or dying

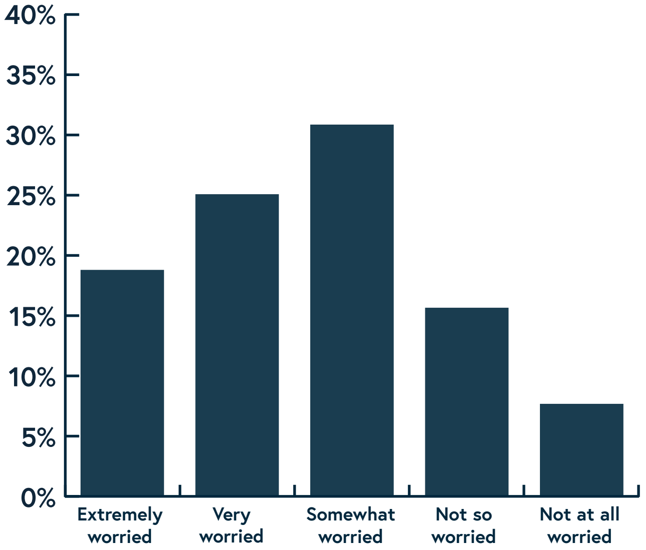
- 61% extremely or very worried
- 25 % somewhat worried



COVID-19 Concern outweighed general health concerns.

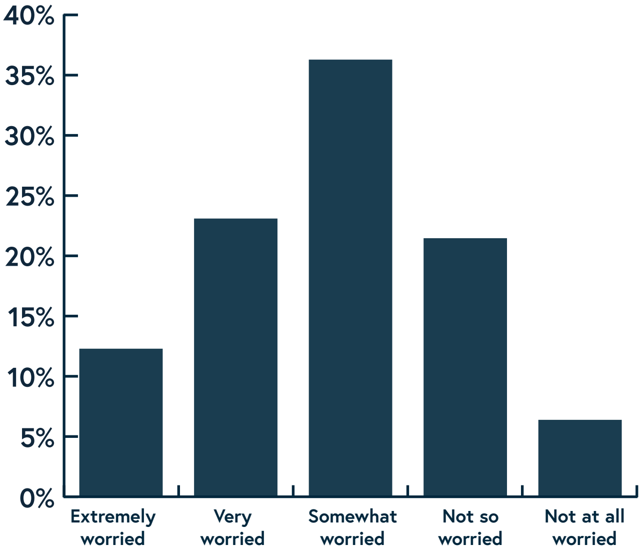
Urgent treatment being delayed

- 45% worried about delays to urgent care
- 30% somewhat worried



Lack of face to face care

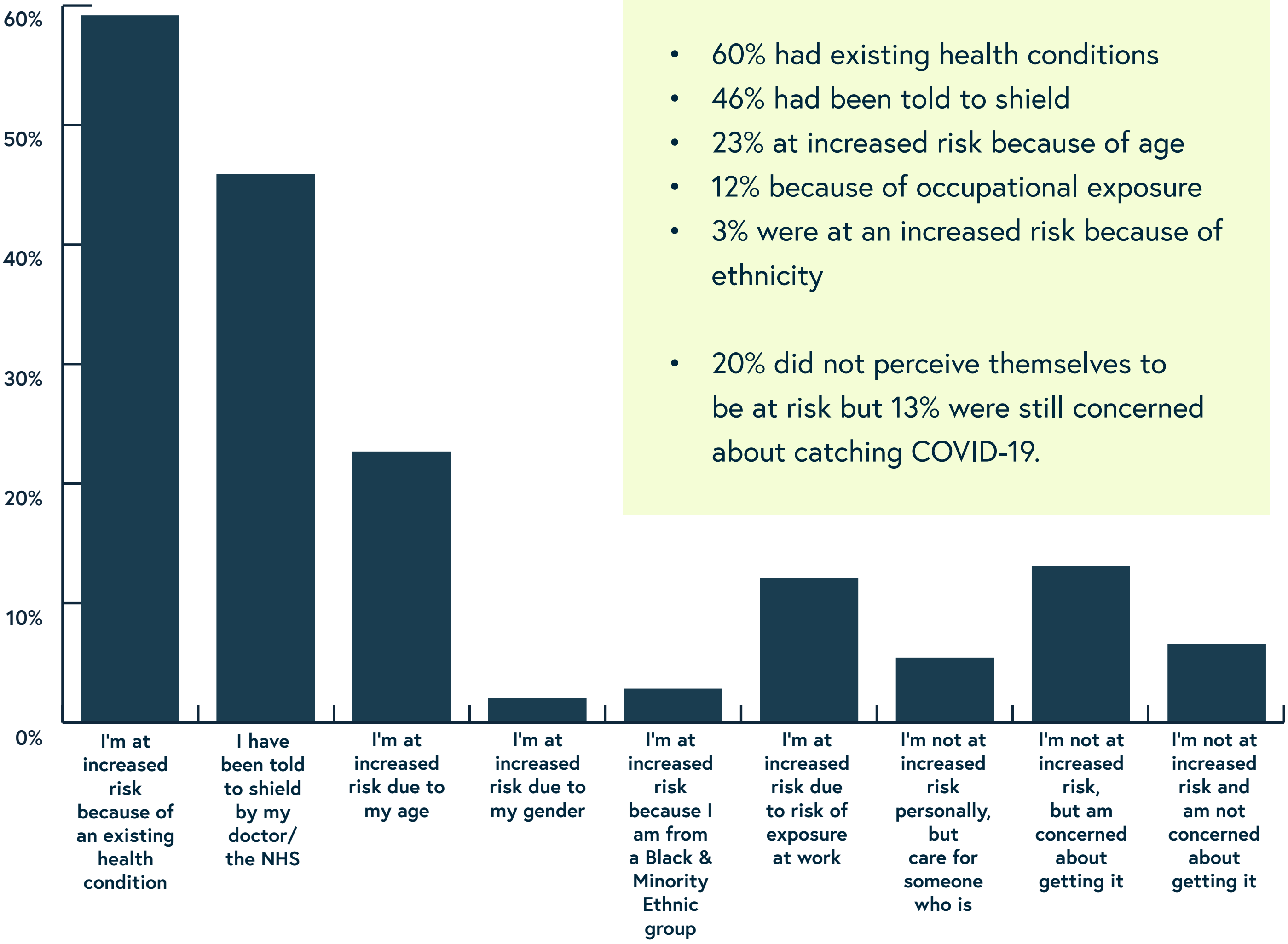
- 35% concerned something would be missed by lack of face to face care
- 30% somewhat worried



Risk factors

- 60% had existing health conditions
- 46% had been told to shield
- 23% at increased risk because of age
- 12% because of occupational exposure
- 3% were at an increased risk because of ethnicity

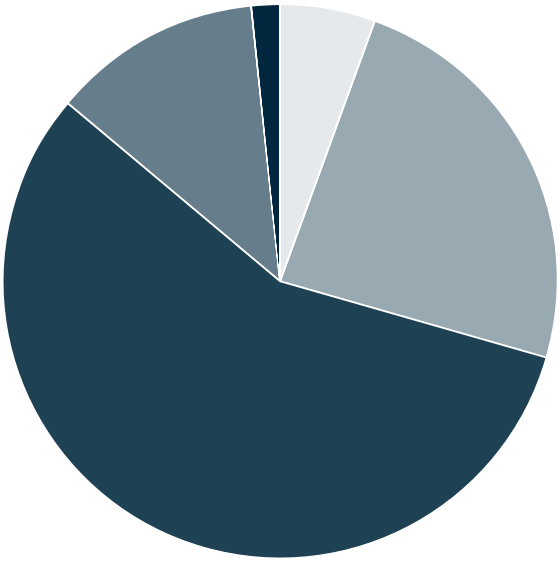
- 20% did not perceive themselves to be at risk but 13% were still concerned about catching COVID-19.



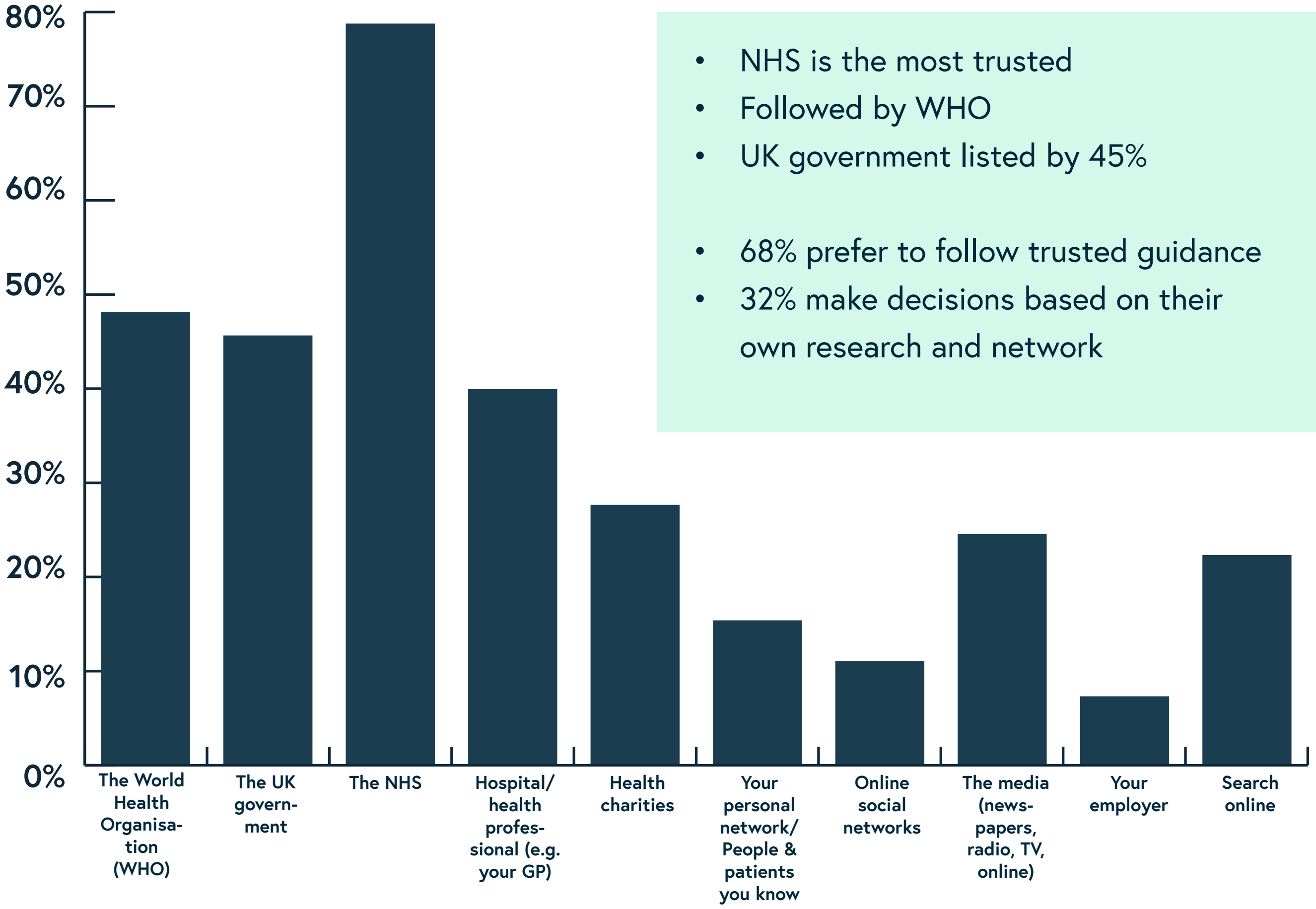
Confidence

- 56% of people were somewhat confident about protecting themselves from COVID-19.
- Only 29% were very confident.

■ 5.58% extremely confident	■ 12.14% not so confident
■ 24.04% very confident	■ 1.49% not at all confident
■ 56.75% somewhat confident	



Trusted information



- NHS is the most trusted
- Followed by WHO
- UK government listed by 45%

- 68% prefer to follow trusted guidance
- 32% make decisions based on their own research and network

- 25% have plenty of trustworthy info
- 53% have just enough to make decisions
- 17% don't have enough information
- 5% are overwhelmed with information and can't make a decision.

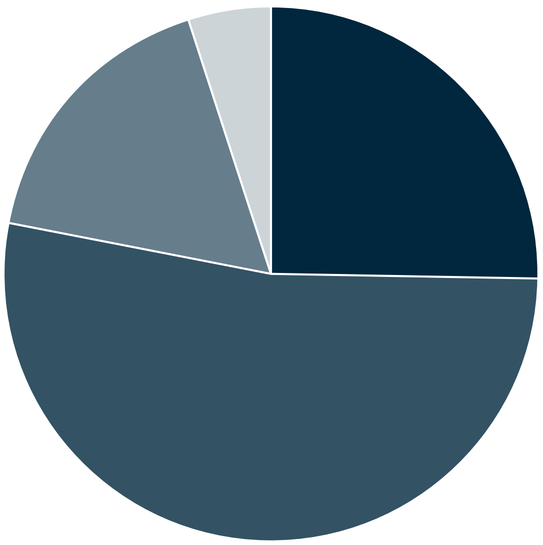
There were 187 free text comments, almost all negative.

■ 25.31%
I have plenty of trustworthy information to make decisions

■ 16.96%
I don't have enough trustworthy information to make decisions

■ 52.87%
I have just about enough trustworthy information to make decisions

□ 4.86%
I feel unable to make a decision because there is too much information



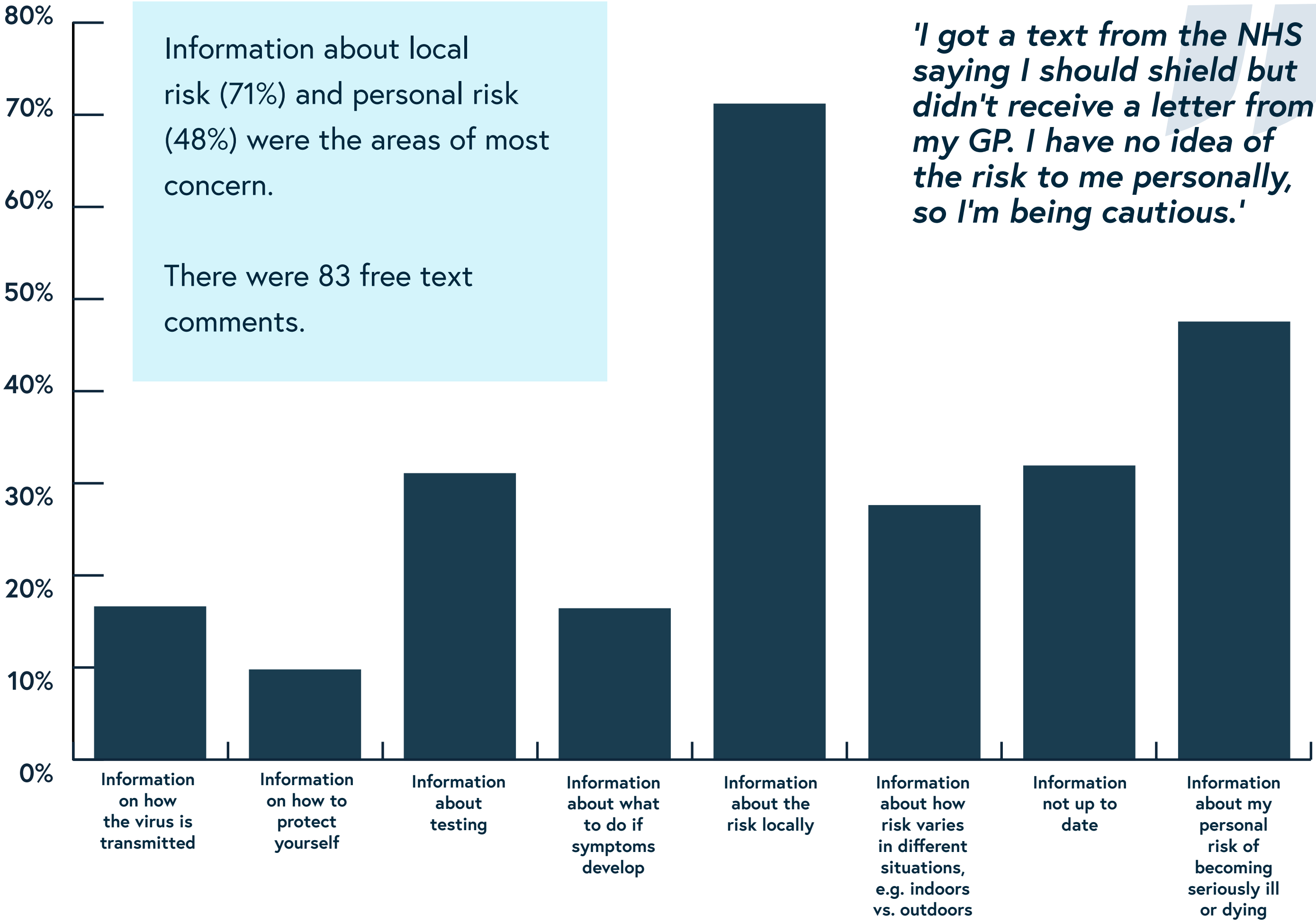
'Not having enough information has caused me to be over cautious and shield. I don't trust the government as I believe their priority is the economy not public health.'

Missing information

Information about local risk (71%) and personal risk (48%) were the areas of most concern.

There were 83 free text comments.

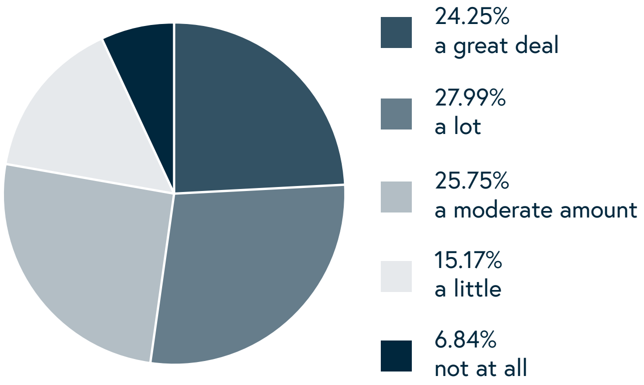
'I got a text from the NHS saying I should shield but didn't receive a letter from my GP. I have no idea of the risk to me personally, so I'm being cautious.'



Conflicting information

Only 7% of people felt information was consistent. 52% found it very conflicting. It was ranked equally difficult as finding trustworthy information.

There were 242 free text comments.



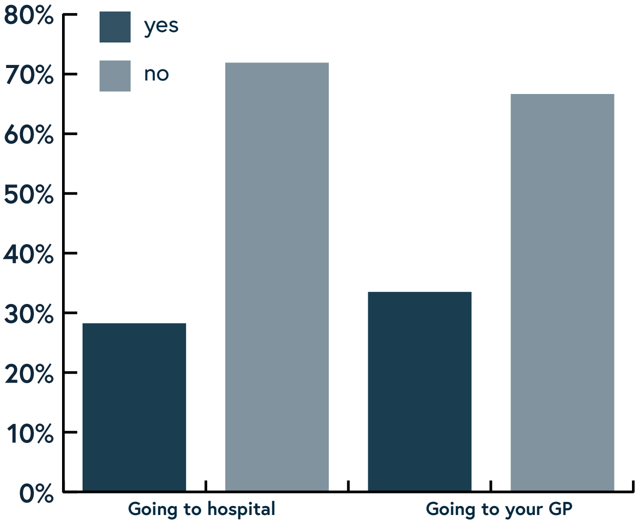
'The government told me to shield, the transplant coordinators told me I could carry on working. My GP told me to do what I want.'

Inconsistent information undermines trust, leading some people to be over cautious to protect themselves. This includes avoiding healthcare.

Accessing healthcare

30% of people delayed seeking treatment, most for Covid concerns.

There were 261 free text comments.



Q18. Have you changed your treatment plans to avoid hospitals or your GP surgery?

> ***'I have avoided all GP visits, and instead self diagnosed and treated the family with off the shelf drugs or DIY remedies (successful fortunately)!'***

> ***'Due a blood pressure check but will not attend to be tested on a machine with an arm cuff that is probably never cleaned. No thank you.'***

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

> ***'I worry about having a video call rather than face to face, but I worry about face to face because of Covid.'***

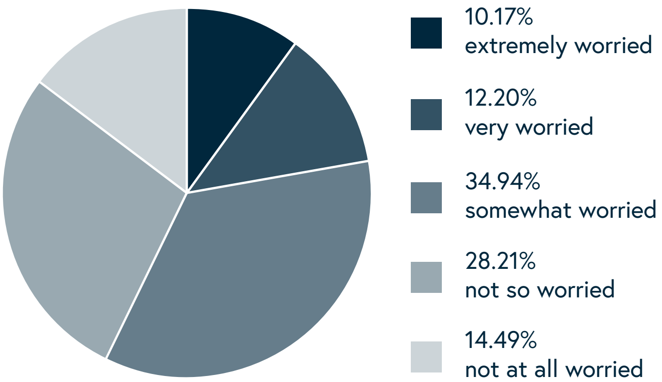
Concern for future appointments

57% had some level of worry about future appointments.

The biggest concerns were:

- Communal waiting areas and corridors
- Public facilities including toilets
- Exposure from staff
- Public transport

The lowest level of concern was about clinical equipment.



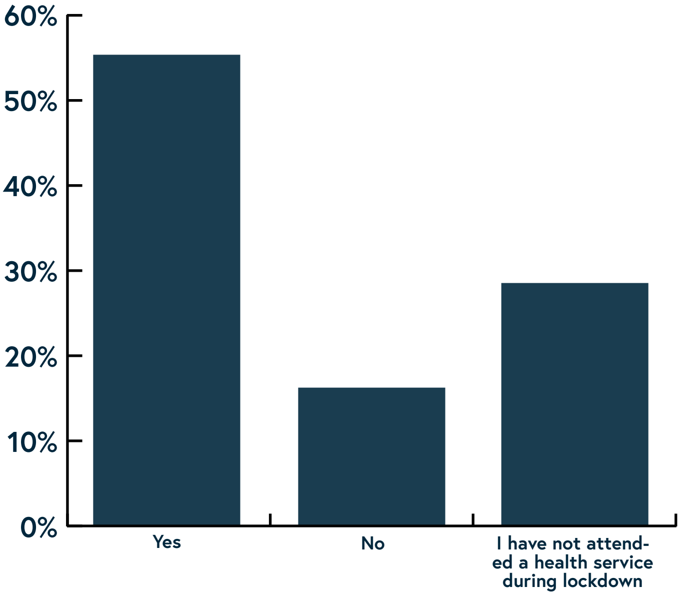
Q22. Thinking about your next appointment, how worried are you about the potential risk involved?

Covid safety measures

Enough information before face to face care

71% had face to face care.

25% did not have prior information about COVID-19 safety measures.



> *'A little information would have stopped my anxiety going through the roof.'*

> *'Wasn't expecting that my carer wouldn't be able to support me in appointments.'*

> *'I only found out about changes after I got there.'*

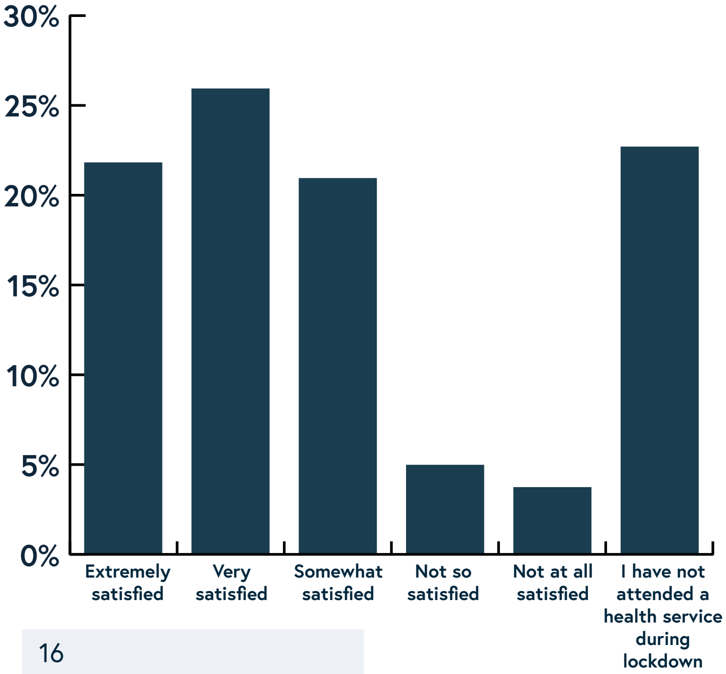
Experience

71% had attended care. Of these:

- 61% were very satisfied about precautions
- 27% were somewhat satisfied
- Only 11% were not satisfied.

Main concerns

- Lack of social distancing/masks in communal areas.
- Lack of cleaning in waiting areas.
- Staff not wearing masks or gloves or using them correctly.
- Lack of separation between COVID-19/non-COVID-19 patients.



Lack of information before appointments causes concern.

Most people's experience is good but there is room for improvement.

Concern about future appointments could be prevented with better information.

Join us

PIF is the independent UK membership body for people working in health information and support. We operate the PIF TICK, the UK-wide quality mark for health information.

We have more than 1,000 members in 300 cross-sector organisations. These include national charities, the NHS, commercial, government, freelance and academic sectors. We use the insight and support of our membership to lobby governments in support of our vision.

Our vision

Everyone has access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care.

Our Partners

Bupa
CANCER RESEARCH UK
HIFA.org Healthcare Information for All
MACMILLAN CANCER SUPPORT
MSD
National Voices
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