Why do patients in the UK not seek help from the doctor, when they should?

The views of over 300 UK patient and health advocacy groups compared with the views of a total of 870 patient groups worldwide

November 2011
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The seven factors that prevent patients going to the doctor when they should:

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Introduction

When patients do not seek help from the doctor, the consequences for the patient (and for society) can be damaging. Patients who are reluctant to visit the doctor do not receive the medicines they need, may not comply with treatment regimes, or may throw away medicines which they think do not work. Patients are not always to blame for failing to go to the doctor when they should. Sometimes, the fault is with the system. However, any delays in seeing the doctor lead to unnecessary sickness and disease, and extra financial burdens to the NHS. The precise cost to society of patients not seeing their doctors remains unknown, but the figures below make uncomfortable reading.

• **Long waiting times.** Over a quarter of patients wait more than a week for an appointment with their doctor\(^1\). In any month of the year, more than 600,000 UK patients are waiting to be admitted to hospital\(^1\).

• **Delayed diagnosis.** Almost two thirds of UK patients who are diagnosed with cancer have had to wait longer than three months between first making an appointment to see their family doctor due to worrying symptoms, and finally being told that they have cancer. The delay proves fatal for many patients\(^2\).

• **Failure to diagnose medical conditions.** Up to half a million people in the UK are estimated to have diabetes and yet remain undiagnosed\(^3\).

• **The cost of missed appointments.** Missed appointments cost the National Health Service (NHS) more than £600m a year\(^4\).

References:
2. [http://www.dailymail.co.uk/health/article-1361269/1-4-cancer-cases-missed-GPs-delaying-vital-treatment.html](http://www.dailymail.co.uk/health/article-1361269/1-4-cancer-cases-missed-GPs-delaying-vital-treatment.html)
Patients fail to go to see the doctor for many of the reasons listed in this report, including shortages of health professionals, and a fear among patients of receiving ‘bad news’. Whatever the cause of patient disinclination to attend, health policymakers must begin to consider the subject if they are to halt growing levels of latent disease in the community, improve patient compliance with treatment, and reduce the amount of medical wastage.

Policymakers who wish to develop sound strategies for encouraging patients to come forward need to have an understanding of the causes behind patient hesitancy to present. PatientView has explored these causes by seeking the opinions of patient groups in and outside the UK. The groups’ viewpoints have helped some ideas to be produced for overcoming the problem of patient reluctance to visit the doctor.

This November 2011 PatientView study
Over the past year, PatientView has been collecting the opinions of patient groups from around the globe on the subject of why patients do not see the doctor when they should. 316 UK patient groups and 554 patient groups from the rest of the world supplied assessments. A special effort was made to gather the evaluations of local community groups, since local organisations function in close proximity to patients. This UK report analyses and categorises the numerous comments of the 316 UK groups into 9 main themes (which, in turn, are based upon 76 identifiable categories). The UK results are compared with the results of the global study. From the pooled evidence and analyses, PatientView suggests a number of strategies that could enhance the efficiency of the NHS by ensuring that patients see their doctors when they should.

Footnotes to the study:
1. When possible, this study distinguishes between primary (GP) doctors and hospital doctors. However, not every patient group supplied such a distinction.
2. Some patient groups offered the study a number of reasons as to why patients do not go to see their doctors. Each different reason has been separately categorised in the study.
3. Unless otherwise indicated, percentages are based on the numbers of respondent patient groups that took part in the study: 316 UK groups out of a global total of 870.
Executive summary

In the UK: the 316 UK patient and health advocacy groups in this study identify 76 causes as to why UK patients do not seek help from their doctors when they should [the 76 separate causes are listed in Appendix II]. The 76 causes can be distilled down to the nine major factors listed below. More details on each of the nine factors (and quotations from patient group respondents) can be found in the rest of the report.

Outside of the UK: patients face additional barriers that hinder them from seeking help from doctors—chief among which is cost. 19%* of patient groups outside the UK say that cost acts as a barrier to some patients. 15% of the groups say that some patients cannot afford the cost of diagnosis or treatment. 4% say that some patients lack sufficient medical insurance/coverage.

1. Fear and stigma: 40% of UK patient (and other health advocacy) groups identify fear and stigma as a barrier that prevents patients from seeking help from the doctor when they should. The equivalent figure among groups around the world is 31%.

2. Lack of faith in the doctor’s capabilities: 28% of UK patient (and other health advocacy) groups say that a lack of patient faith in the abilities of their doctor prevents patients from coming forward for treatment and care when they should. The equivalent figure among groups around the world is 18%.

3. Access to doctors: 25% of UK patient (and other health advocacy) groups believe that difficulties in obtaining an appointment, and in being able to spend sufficient time, with a doctor prevent patients from seeking help from the doctor. The equivalent figure among groups around the world is 18%.

4. Lack of patient awareness of their clinical needs: 18% of UK patient (and other health advocacy groups) say that an unawareness of the need to see a doctor when they should prevents patients from presenting. The equivalent figure among groups around the world is 11%.

Note that the percentages above do not necessarily add up to 100%, as each respondent may have offered more than one reason as to why patients do not present.

* Percentages are based on the 554 groups outside the UK.
5. **Poor doctor-patient relationships**: 17% of UK patient (and other health advocacy) groups see poor doctor-patient relationships as a barrier that prevents patients from seeking help from the doctor when they should. The equivalent figure among groups around the world is 10%.

6. **Psychological or cultural barriers**: 10% of UK patient (and other health advocacy) groups note that psychological or cultural barriers prevent patients from seeing the doctor when they should. The equivalent figure among groups around the world is 9%.

7. **Difficulties face by patients in physically getting to a doctor**: 10% of UK patient (and other health advocacy) groups cite the physical difficulties of getting to the doctor as a barrier to patients seeking necessary medical help. The equivalent figure among groups around the world is 9%.

8. **The doctor does not meet the patient’s needs**: 5% of UK patient (and other health advocacy) groups believe that a failure by the doctor to meet patient expectations prevents those patients from seeking help from the doctor when they should. The equivalent figure among groups around the world is 4%.

9. **Shortage of resources in the healthcare system**: 2% of UK patient (and other health advocacy) groups believe that a shortage of resources in the NHS prevents patients from seeing their doctors when they should. The equivalent figure among groups around the world is 5%.

Note that the percentages above do not necessarily add up to 100%, as each respondent may have offered more than one reason as to why patients do not present.
Some strategic thoughts

- Society needs to overcome the problem of people failing to seek help from their doctor when they should—or face the continued high social and economic costs of people getting sicker unnecessarily. Any positive change that helps to overcome barriers to attendance will produce major cost savings throughout the community (not just within the healthcare budget itself).

- One subject that needs to be tackled is public ignorance of which physical symptoms (associated with the major chronic diseases) should prompt a visit to a GP. The public also needs continued reassurance that early intervention does not result in the patient having to come to terms with terrible news—rather, it saves lives and prevents further sickness. Even cancer, if discovered in time, is no longer the death sentence that it once was.

- The NHS gatekeeper system—though valuable in managing patient demand—has also functioned too much as a brake on fast patient referral, leading to extra levels of sickness, and additional costs to the NHS. Quicker referral rates could prevent much unnecessary sickness and death, especially in people with arthritis, or cancer, diabetes, mental health problems, neurological conditions (such as multiple sclerosis, or fibromyalgia), rare diseases, or respiratory diseases.

- The GP appointment system needs to be overhauled, so that any patient with high clinical priorities can be fast-tracked into the doctor’s office. More time in the consultation procedure needs to be allocated to patients with special communicational disabilities, and translators and British Sign Language (BSL) interpreters made more readily available.

- Doctors need to be trained to communicate more effectively with their patients—some of whom would rather not make an important appointment with their doctor than have to face a professional.

- Above all, patients need to be helped to feel confident that the doctor will only do what is best for them.
1. Fear and stigma

- 40% of all UK responses  • 31% of all global responses

I. The patient fears the doctor and/or the healthcare system

<table>
<thead>
<tr>
<th>Fears</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient fears not being listened to by the doctor</td>
<td>6.3</td>
<td>4.4</td>
</tr>
<tr>
<td>The patient fears being judged by the doctor</td>
<td>2.2</td>
<td>1.7</td>
</tr>
<tr>
<td>The patient fears not being taken seriously by the doctor</td>
<td>2.2</td>
<td>2.0</td>
</tr>
<tr>
<td>The patient fears the doctor will be dismissive or unsympathetic</td>
<td>2.2</td>
<td>0.9</td>
</tr>
<tr>
<td>The patient fears discrimination from within the healthcare system</td>
<td>1.9</td>
<td>2.1</td>
</tr>
<tr>
<td>The patient has had a bad experience with the healthcare system before</td>
<td>1.9</td>
<td>1.6</td>
</tr>
<tr>
<td>The patient fears not being believed by the doctor</td>
<td>1.6</td>
<td>1.6</td>
</tr>
<tr>
<td>The patient fears being reprimanded by the doctor</td>
<td>1.3</td>
<td>1.1</td>
</tr>
<tr>
<td>The patient fears being seen by the doctor as a nuisance, or as neurotic</td>
<td>1.3</td>
<td>0.7</td>
</tr>
<tr>
<td>The patient fears that the doctor will be arrogant and intimidating</td>
<td>0.9</td>
<td>1.0</td>
</tr>
<tr>
<td>The patient fears the doctor’s reaction</td>
<td>0.6</td>
<td>0.5</td>
</tr>
<tr>
<td>The patient fears that the doctor is not interested in them</td>
<td>0.6</td>
<td>0.5</td>
</tr>
<tr>
<td>The patient fears poor staff attitudes in general</td>
<td>0.3</td>
<td>0.2</td>
</tr>
<tr>
<td>The patient fears being made to feel stupid by the doctor</td>
<td>0.3</td>
<td>0.5</td>
</tr>
</tbody>
</table>

Subtotal: 23.6 17.7

II. The patient fears the consequences of having a medical condition

<table>
<thead>
<tr>
<th>Fears</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient fears the medical consequences of a diagnosis</td>
<td>7.6</td>
<td>6.2</td>
</tr>
<tr>
<td>The patient fears stigmatisation, prejudice and discrimination</td>
<td>2.5</td>
<td>3.0</td>
</tr>
<tr>
<td>The patient is ashamed or embarrassed at having the condition</td>
<td>2.2</td>
<td>0.8</td>
</tr>
<tr>
<td>The patient fears the legal consequences of diagnosis</td>
<td>1.6</td>
<td>0.9</td>
</tr>
<tr>
<td>The patient fears discrimination from society at large</td>
<td>0.6</td>
<td>0.5</td>
</tr>
<tr>
<td>The patient fears having to take time off work or becoming unemployed</td>
<td>0.3</td>
<td>0.3</td>
</tr>
</tbody>
</table>

Subtotal: 15.1 12.5

III. The patient fears certain consequences of treatment

<table>
<thead>
<tr>
<th>Fears</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient fears the side effects of medication</td>
<td>0.3</td>
<td>0.9</td>
</tr>
<tr>
<td>The patient fears drug interactions</td>
<td>0.3</td>
<td>0.1</td>
</tr>
</tbody>
</table>

Subtotal: 0.6 1.0
2. Lack of faith in the doctor’s capability

- **28% of all UK responses**  
- **18% of all global responses**

<table>
<thead>
<tr>
<th>Reason</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The doctor lacks clinical knowledge of the patient’s condition</td>
<td>24.4</td>
<td>14.9</td>
</tr>
<tr>
<td>The GP acts as a barrier to the specialist</td>
<td>1.3</td>
<td>1.7</td>
</tr>
<tr>
<td>The patient fears a lack of confidentiality</td>
<td>1.3</td>
<td>0.8</td>
</tr>
<tr>
<td>Different doctors give conflicting advice</td>
<td>0.6</td>
<td>0.3</td>
</tr>
<tr>
<td>The patient fears that the doctor is motivated only by financial considerations</td>
<td>0.6</td>
<td>0.3</td>
</tr>
</tbody>
</table>
3. Poor access to the doctor

- 26% of all UK responses
- 18% of all global responses

<table>
<thead>
<tr>
<th>Issue</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient only receives a short consultation</td>
<td>8.5</td>
<td>9.5</td>
</tr>
<tr>
<td>Difficulty in scheduling an appointment acts as a barrier to the patient</td>
<td>6.0</td>
<td>3.1</td>
</tr>
<tr>
<td>Waiting times for an appointment with the doctor are too long</td>
<td>2.5</td>
<td>0.3</td>
</tr>
<tr>
<td>Getting a correct diagnosis or the balance of treatment takes too long</td>
<td>2.5</td>
<td>1.7</td>
</tr>
<tr>
<td>The patient is unable to get an appointment time that suits their lifestyle</td>
<td>1.9</td>
<td>0.9</td>
</tr>
<tr>
<td>Carers have a particular problem in finding the time to see the doctor</td>
<td>1.9</td>
<td>0.7</td>
</tr>
<tr>
<td>Specific difficulties in accessing the specialist</td>
<td>1.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Waiting times for an appointment with the GP are too long</td>
<td>1.0</td>
<td>0.6</td>
</tr>
<tr>
<td>Waiting times for an appointment with the specialist are too long</td>
<td>0.3</td>
<td>0.2</td>
</tr>
</tbody>
</table>
4. The patient’s lack of awareness of their clinical needs

- **18% of all UK responses**  •  **11% of all global responses**

<table>
<thead>
<tr>
<th>Reason</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient is aware of having a medical condition—but lacks the knowledge needed to proceed further</td>
<td>7.0</td>
<td>4.0</td>
</tr>
<tr>
<td>A category of patient who may not take care of their own health: carers</td>
<td>4.1</td>
<td>0.1</td>
</tr>
<tr>
<td>The patient is aware of having a medical condition—but does not see any point in seeking diagnosis or treatment</td>
<td>2.8</td>
<td>2.6</td>
</tr>
<tr>
<td>The patient is in a state of denial about their condition</td>
<td>2.5</td>
<td>3.2</td>
</tr>
<tr>
<td>The patient is not aware of having a medical condition</td>
<td>0.9</td>
<td>1.0</td>
</tr>
<tr>
<td>The patient may not take care of their own health</td>
<td>0.3</td>
<td>0.2</td>
</tr>
</tbody>
</table>
5. Poor doctor-patient relationships

- 17% of all UK responses  • 10% of all global responses

I. The patient is too submissive to the doctor

<table>
<thead>
<tr>
<th>Reason</th>
<th>UK %</th>
<th>Global %</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient does not want to bother the doctor</td>
<td>3.8</td>
<td>1.8</td>
</tr>
<tr>
<td>The patient feels overawed by the doctor, who can be patronising or patriarchal</td>
<td>3.2</td>
<td>2.8</td>
</tr>
<tr>
<td>The patient does not want to waste the doctor’s time</td>
<td>1.9</td>
<td>1.1</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>8.9</strong></td>
<td><strong>5.7</strong></td>
</tr>
</tbody>
</table>

II. Poor doctor-patient communication

<table>
<thead>
<tr>
<th>Reason</th>
<th>UK %</th>
<th>Global %</th>
</tr>
</thead>
<tbody>
<tr>
<td>The doctor lacks communication skills</td>
<td>2.8</td>
<td>2.3</td>
</tr>
<tr>
<td>The doctor is poor at communicating with patients who have a communication disability</td>
<td>1.9</td>
<td>0.7</td>
</tr>
<tr>
<td>The patient fears being denied informed consent</td>
<td>0.6</td>
<td>0.8</td>
</tr>
<tr>
<td>Being honest with the doctor is impossible—whatever the reason</td>
<td>0.6</td>
<td>0.2</td>
</tr>
<tr>
<td>The patient has a poor relationship with the doctor</td>
<td>0.3</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>6.3</strong></td>
<td><strong>4.6</strong></td>
</tr>
</tbody>
</table>

III. Lack of continuity of care

<table>
<thead>
<tr>
<th>Reason</th>
<th>UK %</th>
<th>Global %</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient is not permitted to see the same doctor</td>
<td>1.9</td>
<td>0.1</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>1.9</strong></td>
<td><strong>0.1</strong></td>
</tr>
</tbody>
</table>

Executive summary

Why do UK patients not seek help from doctors when they should?
6. Psychological and cultural barriers

- **10% of all UK responses**  
- **9% of all global responses**

<table>
<thead>
<tr>
<th>Reason</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language and cultural barriers inhibit the patient from going to the doctor</td>
<td>2.8</td>
<td>2.3</td>
</tr>
<tr>
<td>Men are particularly reluctant to visit the doctor</td>
<td>2.2</td>
<td>1.5</td>
</tr>
<tr>
<td>The patient is afraid to admit failings in compliance</td>
<td>1.6</td>
<td>2.4</td>
</tr>
<tr>
<td>The patient lacks the confidence to go (or relate) to the doctor</td>
<td>1.3</td>
<td>1.3</td>
</tr>
<tr>
<td>People do not like to go to the doctor</td>
<td>0.9</td>
<td>0.7</td>
</tr>
<tr>
<td>The patient’s carers may lack understanding or communicational skills</td>
<td>0.9</td>
<td>0.6</td>
</tr>
<tr>
<td>Family considerations may inhibit the patient from going to the doctor</td>
<td>0.6</td>
<td>0.3</td>
</tr>
</tbody>
</table>
# 7. Physical barriers in getting to (or being with) the doctor

- 10% of all UK responses  
- 9% of all global responses

<table>
<thead>
<tr>
<th>Physical barrier</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient’s own health problems may make visiting the doctor difficult</td>
<td>2.2</td>
<td>1.6</td>
</tr>
<tr>
<td>Gaining entry into healthcare infrastructure is difficult for people with a disability</td>
<td>2.2</td>
<td>0.9</td>
</tr>
<tr>
<td>The patient’s transport problems may make visiting the doctor difficult</td>
<td>1.6</td>
<td>2.3</td>
</tr>
<tr>
<td>The physical mechanisms involved in booking an appointment may make visiting the doctor difficult</td>
<td>1.3</td>
<td>0.6</td>
</tr>
<tr>
<td>The patient lacks the time to visit the doctor</td>
<td>0.6</td>
<td>0.8</td>
</tr>
<tr>
<td>Patients in rural areas find travel to the doctor particularly difficult</td>
<td>0.6</td>
<td>0.6</td>
</tr>
<tr>
<td>The doctor’s distance from the patient may make visiting the doctor difficult</td>
<td>0.3</td>
<td>1.6</td>
</tr>
<tr>
<td>The cost of travel to the doctor may make visiting the doctor difficult</td>
<td>0.3</td>
<td>0.8</td>
</tr>
<tr>
<td>The facility’s secretarial or booking staff act as a barrier to the patient</td>
<td>0.3</td>
<td>0.1</td>
</tr>
<tr>
<td>The doctor is not willing to see a younger patient</td>
<td>0.3</td>
<td>0.1</td>
</tr>
</tbody>
</table>
8. The patient’s needs are not met

- **5% of all UK responses**  
- **4% of all global responses**

<table>
<thead>
<tr>
<th>Condition/Need</th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient has a condition that is not medically recognised or accepted</td>
<td>3.2</td>
<td>2.2</td>
</tr>
<tr>
<td>The doctor does not prescribe the treatment that the patient wishes</td>
<td>1.3</td>
<td>1.2</td>
</tr>
<tr>
<td>The doctor ignores the patient’s or carer’s needs</td>
<td>0.6</td>
<td>0.2</td>
</tr>
</tbody>
</table>
9. Shortage of healthcare resources

- 2% of all UK responses  
- 5% of all global responses

<table>
<thead>
<tr>
<th></th>
<th>% UK</th>
<th>% Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>The healthcare system lacks resources</td>
<td>0.9</td>
<td>1.3</td>
</tr>
<tr>
<td>Lack of specialists</td>
<td>0.3</td>
<td>1.6</td>
</tr>
<tr>
<td>Lack of both primary-care doctors and specialists</td>
<td>0.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Lack of primary-care doctors</td>
<td>0.3</td>
<td>0.8</td>
</tr>
</tbody>
</table>
1. Fear and stigma

40% of patient and other health advocacy groups identify fear or stigma as a barrier that prevents people from seeking help from their doctor.
Three main types of fear or stigmatisation are felt by patients

• **24% of UK patient and health advocacy groups state that patients fear the reaction of the doctor (or the healthcare system)**

  A few patient groups (2%) believe that patients who have had bad experiences with the healthcare system previously will be reluctant to return. 6% of patient groups (representing mostly the interests of patients with arthritis, endocrine disorders, mental health problems, or neurological conditions) believe that patients do not attend the doctor because they may fear that the doctor will not listen to them. 2% of groups say that patients may think the doctor will not take their concerns seriously. A further 2% say that patients think the doctor will be dismissive or unsympathetic. In some cases, a parent or carer, or a patient who has difficulty explaining themselves, can feel ignored by the doctor. Another 2% of groups believe that patients do not go to the doctor because their views, although listened to by the doctor, are not then taken seriously—an issue raised by cancer groups, older people’s groups, young people’s groups, and carers’ groups. One in five of the groups think that patients do not go to the doctor because their accounts of their symptoms and experiences will not be believed by the doctor. A few groups (2%—chiefly groups representing the interests of people with a mental health or sexual health problem) think patients worry about being judged by the doctor, while a further 2% believe that patients fear being stigmatised by the doctor or healthcare system because of the medical condition they have (HIV/AIDS and mental health problems figure prominently under this category). The remaining 6% of patient groups say that patients will not go to the doctor for fear of being reprimanded, worry about upsetting the doctor, of drawing some other negative reaction, being seen as a nuisance, or that the patient fears the doctor will be arrogant and intimidating, or disinterested in their situation.

• **15% of the patient groups say that patients fear the consequences of having a medical condition**

  Patients may be reluctant to visit the doctor because they fear being told that they have a serious medical condition (a particular concern of people who suspect that they may have cancer), or that they fear the embarrassment which can result from being diagnosed (a foreboding among people who have a sexual health or urinary problem), or they fear social prejudice and impact on their employment or other aspects of their life (a worry among people who suspect that they have a mental health problem).

• **Two groups (0.6% of the UK groups) think that patients fear certain consequences of treatment**

  Only two of the patient groups mention that patients may be so upset by the thought of having to cope with drug side-effects (mentioned by a mental health group) or drug interactions (mentioned by an HIV/AIDS group) that they do not wish to come forward for care.
Strategies to overcome the fear and stigma that prevents patients from approaching their doctors

• Doctors need to be trained to learn how to listen, and communicate with, patients from all walks of life.

• Patients need to be better informed of the treatment-and-care pathways that follow a diagnosis, so they are not inhibited in coming forward.

• The public needs to be made more aware that cancer is no longer a guaranteed killer.

• Public education (including in the workplace) is needed to help de-stigmatise mental health conditions.

• Patients need assurance that their mental health status is a medically confidential matter.

• Patients need to be provided with greater support in self-managing their medical condition—with the aim of ensuring that they know when to look after themselves, and when to go and see the doctor.
The patient fears not being listened to by the doctor [20 references]:

"Not feeling listened to."
—Anonymous. Asthma (including COPD). Local or regional. UK.

"Doctors do not listen; they always know best."
—British Thyroid Foundation, Oxon Thyroid Group. Thyroid deficiencies (hypo and hyper). Local or regional. UK.

"They feel that the doctor doesn’t listen. Often the message from the doctor is: “It’s arthritis, learn to live with it”, or “There is nothing we can do.”"
—Arthritis Care, Watford Branch. Arthritis (including ankylosing spondylitis). Local or regional. UK.

"They are not listened to."
—Anonymous. Carer/parent. Local or regional. UK.

"Feeling that doctors do not always listen to their concerns."
—Anonymous. Carer/parent. Local or regional. UK.

"Feeling that they are not listened to, that doctors ‘can’t be bothered’."
—Anonymous. Depression. Local or regional. UK.

"Not feeling properly listened to."
—People's Forum. Mental health. Local or regional. UK.

"Patients lack the ability to communication their needs fully to the doctor without support. They then feel that the doctor is not listening."
—Anonymous. Mental health. Local or regional. UK.

"Patients feels as though the doctor will not listen to them."

"The doctors do not listen to needs."
—Anonymous. Multiple sclerosis. Local or regional. UK.

"There is still the attitude of professional knows best—they seem unable to listen and hear what clients say."

"Patients often say “The doctor doesn’t listen; he won’t do anything”, so they don’t go."
—Anonymous. Stroke. Local or regional. UK.

"Fear of not being listened to, or understood."

"Not all GPs listen to the patient properly. People with speech problems find it particularly difficult."

"The GP doesn’t listen to me. My results are normal, but why do I still feel ill?"
—Anonymous. Thyroid deficiencies (hypo and hyper). National. UK.

"Doctors not listening to parents or carers."
—Swale ASD Support Group. Local or regional. UK.

"Not listening to the needs of patients."

"They do not feel that their concerns are listened to, or given equal weight with those of the medical professionals."
—Consultation and Advocacy Promotion Service. Local or regional. UK.

"Not being listened to."

"Usually, it is because the carer is caring at home for someone. In a hospital setting, the carer does not often get a chance to talk to any clinician; in fact, are often ignored."
—Suffolk Family Carers Carer/parent. Local or regional. UK.
I. Fearing the doctor and/or the healthcare system

The patient fears being judged by the doctor [7 references]:

“Fear of being judged on their sexual behaviours.”
—OUR Project. HIV/AIDS. Local or regional. UK.

“Fear of judgement.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“They are sometimes uncertain of the response they will get from a GP regarding an HIV diagnosis, and are worried about being judged. They usually feel safer with HIV specialist clinicians (though this is not always the case).”
—Anonymous. HIV/AIDS. Local or regional. UK.

“A real feeling and experience of being judged.”

“Fear of judgement.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“Judgemental.”
—Anonymous. Sexual diseases. Local or regional. UK.

“Many survivors of child abuse have medical problems that arise from their abuse, but dare not mention, for fear of judgement.”
—Aurora Health Foundation. National. UK.

The patient fears not being taken seriously by the doctor [7 references]:

“Fear that their concerns will not be taken seriously.”
—Anonymous. Cancer (with life expectancy of less than five years), excluding rare cancers. National. UK.

“Doctors do not take them seriously. People who may be the main carers for a patient often say that doctors do not take enough account of their views.”
—Anonymous. Carer/parent. Local or regional. UK.

“Young carers who care for their parents 24/7 are often disregarded by doctors when they take their parent to appointments. The doctors are unwilling to discuss health issues with the children, even although it is they who will have to deal with the issue.”
—Anonymous. Carer/parent. Local or regional. UK.

“Carers often feel they are not taken seriously when they request help for the person they are caring for.”
—Anonymous. Carer/parent. Local or regional. UK.

“Our client group often feels they are not taken seriously. There are some unhelpful attitudes among some professionals.”
—Age Concern, Brighton, Hove and Portslade. Older people (any issues). Local or regional. UK.

“They are generally worried that they will not be taken seriously.”
—Cystitis and Overactive Bladder Foundation. Urinary (including cystitis and painful bladder). International. UK.

“Our speciality is children and young people. They often feel that their GP, for instance, does not take their problems seriously, and does not understand mental health problems. So, they have to become very ill before they are taken seriously. This doesn’t encourage attendance.”
—YoungMinds. National. UK.
The patient fears that the doctor will be dismissive or unsympathetic [7 references]:

“Fear of being dismissed by doctors.”
—Aurora Health Foundation. National. UK.

“Doctors being dismissive, ignoring physical complaints as mental health complaints, when they are not. Doctors not reading notes about the patient, and constantly asking the same questions.”

“Doctors tend to be unsympathetic, and dismiss illness as minor, or the patient as neurotic.”
—British Thyroid Foundation, Oxon Thyroid Group. Thyroid deficiencies (hypo and hyper). Local or regional. UK.

“Unsympathetic treatment.”
—Edinburgh Young Carers Project. Local or regional. UK.

“Some doctors have a very bad attitude towards their patients. They treat and talk to them like they are not worth anything, and as if the patients are just taking up their time.”
—Anonymous. Local or regional. UK.

“Patients are often dismissed, as it is only aches and pains—so, get on with it.”

“Some patients feel that their doctor does have a negative attitude towards their hearing loss.”
—deafPLUS Deafness. Local or regional. UK.

The patient fears discrimination from within the healthcare system [6 references]:

“HIV stigma from the medical professionals.”
—Begin at Yorkshire Mesmac. HIV/AIDS. Local or regional. UK.

“Prejudice from doctors, depending on patient origin (for instance, doctors assume that patients from sub-Saharan Africa are suffering from HIV-related illness).”
—Terrence Higgins Trust. HIV/AIDS. National. UK.

“Many of our clients are reluctant to involve their GP in their care, because they feel that their HIV status counts against them.”
—The Eddie Surman Trust. HIV/AIDS. National. UK.

“Patients do not always disclose to their doctor, as most doctors often are prejudiced.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“It may involve having to come out as a gay man, drug user, etc, when they are nervous of doing so, and do not trust the doctor’s response—fears of prejudice.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“Fear of stigma is a major barrier to seeking help, as not all GPs understand severe mental illness, and stigma in public attitudes is still so strong.”
I. Fearing the doctor and/or the healthcare system

The patient has had a bad experience with the healthcare system before [6 references]:

“Bad previous experiences of healthcare professionals not supporting or helping adequately.”

“Within our client group, social anxiety is a major barrier to approaching doctors and being open with them. Previous bad experiences of doctors not taking their anxiety seriously enough, or not showing that they care effectively enough, makes patients reluctant.”
—Anonymous. Anxiety. Local or regional. UK.

“Previous experience of consultations.”
—Anonymous. Asthma (including COPD). Local or regional. UK.

“Previous experience of not being listened to.”
—Anonymous. Learning difficulties (including autism). Local or regional. UK.

“Experience of previous poor quality results.”
—Anonymous. Mental health. Local or regional. UK.

“Preconceived attitudes that have developed from previous bad experiences.”

The patient fears not being believed by the doctor [5 references]:

“Fear of not being believed.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“This section of patients has little faith in the UK’s National Health Service (NHS), and feel that their multiple and fluctuating symptoms are not always believed.”
—25% ME Group—support for severe ME sufferers. Chronic fatigue syndrome. National. UK.

“They get the feeling that some consultants do not believe what patients are telling them.”
—Anonymous. Heart disease (congestive). Local or regional. UK.

“Because mental health is a hidden illness, many patients feel that they will not be believed.”

“Doctors tend to discount what you say if you have a mental health problem. Many physical problems are ignored, because doctors don’t believe its real.”
—Anonymous. Mental health. Local or regional. UK.
I. Fearing the doctor and/or the healthcare system

The patient fears being reprimanded by the doctor [4 references]:

“Afraid of a rebuff.”
—Torbay Prostate Support Association. Cancer (with life expectancy of less than five years), excluding rare cancers. Local or regional. UK.

“Fear of reprimand.”
—Anonymous. Sexual diseases. Local or regional. UK.

“Fear of being told off by healthcare professionals.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“Probably fear that they will be told off.”

The patient fears being seen by the doctor as a nuisance, or as neurotic [4 references]:

“They do not want to appear a nuisance.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Fear of being seen as a nuisance.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“A fear of being classed as a hypochondriac.”
—Anonymous. Rare cancers. Local or regional. UK.

“Parents of ex-premature/sick newborns often feel that their GP treats them as neurotic when raising concerns which would have been regarded as valid within a neonatal unit.”
—Anonymous. Premature and sick newborns. Local or regional. UK.

“They do not want to appear a nuisance.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.
I. Fearing the doctor and/or the healthcare system

The patient fears that the doctor will be arrogant and intimidating [3 references]:

"Intimidation by some doctors prevents clients talking frankly to their doctor."
—Anonymous. Local or regional. UK.

"Sometimes, patients feel intimidated by the doctor's knowledge and status."
—Anonymous. Local or regional. UK.

"In most cultures from the developing world, the doctor is the one who knows better—never challenge a doctor, or your life is in danger."
—Innovative Vision Organisation. HIV/AIDS. Local or regional. UK.

The patient fears the doctor's reaction [2 references]:

"They are afraid of the doctor's attitude."
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

"Many patients do not want to upset, or have a bad relationship with, the GP."
—Anonymous. HIV/AIDS. Local or regional. UK.

The patient fears that the doctor is not interested in them [2 references]:

"Too much apathy, as the doctor does not always show interest."
—Anonymous. Diabetes. UK.

"Doctors, in my personal experience, have lost the care factor. You are made to feel like a target."
—Anonymous. Disability (excluding eyesight, deafness or speech). National. UK.

The patient fears poor staff attitudes in general [1 reference]:

Attitudes of some primary-care staff."
—Anonymous. HIV/AIDS. Local or regional. UK.

"Patients are made to feel stupid. Patients do try very hard to cope, so are dismissed."
—Arthritis Care. Arthritis (including ankylosing spondylitis). National. UK.
The patient fears the medical consequences of a diagnosis [24 references]:

“Fear of what the diagnosis might be.”
—Bosom Friends (Oxfordshire BC Support Group). Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Fear.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Fear.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Not talking to the GP through fear of the illness they believe they have.”
—Breast Cancer Action Group Wolverhampton. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Minimising symptoms in the hope that they are unimportant.”
—Anonymous. Cancer (with life expectancy of less than five years), excluding rare cancers. Local or regional. UK.

“Fear of investigations (particularly relevant for men).”
—Anonymous. Cancer (with life expectancy of less than five years), excluding rare cancers. National. UK.

“Fear of what it could mean to be involved (so that, if they do nothing, it might go away). They fear being told the worst, so it is better not to know at all.”

“Fears for the future.”
—Anonymous. Diabetes. Local or regional. UK.

“Fear of the unknown. Anticipation of being admitted back to hospital for further investigations.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“If poorly, they may be admitted for treatment, and they may not want this at that time.”

“They know that they will be asked to make changes in their lifestyle—which they do not want to do.”

“Fear of a positive diagnosis.”

“Fear of the diagnosis.”
—Anonymous. Breast cancer. Local or regional. UK.

“Fear about the diagnosis.”

“Research has shown that a great many teenagers and young adults who are developing cancer often delay visiting their doctor when they are aware of a problem due to personal fear.”

“Fear of the outcome is often relevant.”
—Anonymous. Breast cancer. Local or regional. UK.

“Reluctance to accept what procedure might have to be imposed.”
—Bosom Friends (Oxfordshire BC Support Group). Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.
II. Fearing the consequences of having a medical condition

The patient fears the medical consequences of a diagnosis [24 references]:

“Fear of mental illness, and being labelled.”
—Bright. Mental health. National. UK.

“Frightened of being sectioned.”
—Anonymous. Mental health. Local or regional. UK.

“Fear of repercussions. For example, being placed on section.”
—Anonymous. Mental health. Local or regional. UK.

“Fear of the outcome (mental health issues, and compulsory treatment).”
—Anonymous. Mental health. Local or regional. UK.

“Concern that they may be compulsorily admitted to hospital.”
—Anonymous. Mental health. Local or regional. UK.

“We are worried we will be sectioned.”
—HUG. Mental health. Local or regional. UK.

“Threat of admission.”
—People’s Forum. Mental health. Local or regional. UK.

The patient fears stigmatisation, prejudice and discrimination [8 references]:

“Stigma.”
—OUR Project. HIV/AIDS. Local or regional. UK.

“Stigma.”
—Anonymous. HIV/AIDS. National. UK.

“Stigma.”
—Barnet Voice for Mental Health. Mental health. Local or regional. UK.

“Stigma.”
—Bright. Mental health. National. UK.

“Stigma regarding mental health issues.”
—Anonymous. Mental health. Local or regional. UK.

“Stigma about their sexual problem.”

“Stigma.”

“Racism.”
—Anonymous. Mental health. Local or regional. UK.
II. Fearing the consequences of having a medical condition

The patient is ashamed or embarrassed at having the condition [7 references]:

“Embarrassment.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Embarrassment.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Embarrassment factor.”
—Anonymous. Sexual diseases. Local or regional. UK.

“Embarrassment.”
—Anonymous. Stroke. Local or regional. UK.

“Acute embarrassment and shame about the condition.”
—UK Paruresis Trust. National. UK.

“To be ashamed of their illness.”
—Barnet Voice for Mental Health. Mental health. Local or regional. UK.

“Embarrassment.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

Diagnosis and treatment may lead to unpleasant social consequences for the patient [5 references]:

“Reluctance to accept the impact of diagnosis on lifestyle, by disrupting an already difficult and complex life.”
—Bosom Friends (Oxfordshire BC Support Group) Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“It not fitting with their own priorities and circumstances.”

“Concerns that independence will be taken away.”
—Anonymous. Older people (any issues). Local or regional. UK.

“Fear of what would be put on their records after a diagnosis.”
—Anonymous. Local or regional. UK.

“You fear being ostracised.”
—Anonymous. Mental health. Local or regional. UK.
II. Fearing the consequences of having a medical condition

**The patient fears the legal consequences of diagnosis [2 references]:**

“Immigration controls.”
—Anonymous. HIV/AIDS. National. UK.

“Concerns about not being able to access treatment among asylum seekers and people who have overstayed their visas.”
—Herts Aid. Sexual diseases. Local or regional. UK.

**The patient fears discrimination from society at large [1 reference]:**

“Stigma within society. They do not want to be labelled with mental health problems.”
—Anonymous. Mental health. Local or regional. UK.

**The patient fears having to take time off work or becoming unemployed [1 reference]:**

“The patient does not want to take time off work.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.
III. Fearing the consequences of treatment

"Fear of being put on to new or additional medication which may have adverse or unpleasant side-effects."
—Anonymous. Mental health. Local or regional. UK.

"Many patients worry that any prescribed medication given by the GP will interact with their HIV medication."
—Anonymous. HIV/AIDS. Local or regional. UK.
2. Lack of faith in the doctor’s capabilities

28% of patients (and other health advocacy groups) say that patients do not come forward for treatment and care when they should because they lack faith in the ability of their doctor.
Lack of faith in the doctor’s capabilities

• 24% of UK patient and health advocacy groups state that patients suspect the doctor lacks knowledge about their clinical condition

This patient concern ranks highest among the 76 categories of reasons provided by UK patient groups as to why patients do not see their doctors when they should. The same findings is true for patient groups outside the UK—25% of which state that patients worry about whether the doctor will know enough about their clinical condition. The groups reporting this patient anxiety cross a broad spectrum of health interests, and include organisations interested in arthritis, cancer, carers, chronic fatigue syndrome, congenital conditions, diabetes, disabilities, fibromyalgia, heart conditions, HIV/AIDS, mental health problems, multiple sclerosis, rare diseases, respiratory conditions, skin conditions, and renal conditions. Patients lack trust in the abilities of the doctor (mainly the GP) for the following reasons:

• Lack of knowledge and understanding by the doctor of a patient’s underlying medical condition (in its various forms), and of the treatment and care required.
• Lack of knowledge by the doctor of the lifestyle changes needed by a patient (for example, after diagnosis with diabetes).
• The doctor cites patient behaviour (for example, smoking, non-compliance with treatment) as the cause of ill-health.
• Lack of respect by the doctor for carers, and for patients’ own understanding of the medical condition.
• Failure of the GP to diagnose correctly, forcing the patient to make return appointments.
• Misdiagnosis by an inexperienced doctor.
• Failure of the GP to recognise the need for speedy referral.
• Lack of knowledge by the doctor of the special difficulties faced by people with a disability.
• The inability of the doctor to regard the patient as a whole person, rather than just as a set of symptoms.
• In some circumstances, an over-dependency by the doctor on drug treatment (such as in case of mental health problems).

• Four groups (1.3% of the UK groups) describe the GP as a barrier to patient access to specialists

One national arthritis group, one national rare disease group, one regional breast cancer group, and one heart group state that GPs hinder patient access to consultants (even when official guidelines emphasise the necessity of referral).

• Four groups (1.3% of the UK groups) say that a perceived lack of confidentially prevents patients from coming forward for care

Two sexual health groups, one stroke group, and an NHS Local Involvement Network (LINKs) refer to a lack of privacy about the process of accessing doctors, and to fears that a centralised medical records system offers little protection to individuals’ privacy.

• Two groups (a prostate cancer group and a blood disorder group) say that patients lose confidence in a healthcare system when different doctors give conflicting advice

• Two groups (a prostate cancer group and a local general health group) see financial considerations behind a failure by doctors to perform clinical duties
Strategies to address patients’ lack of faith in the doctor’s capability

Alarminglly, patient groups seem to believe that a significant numbers of patients have relatively little confidence in the clinical capabilities of their doctors (mostly GPs). Disaffected patients react by not seeing their doctors (even when they need medical attention).

The situation is partly the result of a major drawback with the gate-keeping structure of the UK National Health Service (NHS)—which is that no gate-keeping doctor could ever hope to accumulate a satisfactory knowledge of the unlimited number of diseases and conditions likely to be encountered in patients during the course of a medical career. The fact that primary-care doctors know even as much as they do is a testament to the skills of the profession. Unfortunately, those knowledge levels do not appear to be enough to satisfy all patients.

Gate-keeping, however, cannot be the whole explanation for patient belief that doctors lack knowledge of certain conditions, since a similarly large percentage of patient groups from outside the UK—where gate-keeping is not the norm—also express concern about the state of clinical know-how in their specialty area.

Beyond extra training for primary-care doctors, one other action could ensure better patient care, according to the respondent patient groups. GPs could become more proactive in referring patients to specialists. Of course, with UK GPs holding the purse strings and mindful of budget, such a move could be difficult. Nonetheless, if the overall costs to both the healthcare system and to society as a whole are considered as a result of patients failing to see their doctor when they should, a good economic case could be made for increased levels of referrals.
The doctor lacks clinical knowledge of the patient's condition [77 references]:

"Lack of awareness about arthritis by the GP (who is often not sufficiently informed or trained on musculoskeletal conditions). With over 200 forms of arthritis, and daily fluctuations in the condition, patients, particularly with inflammatory/rheumatoid arthritis, would not contact their GP, as most GPs' understanding of the condition is limited."

— Arthritis Care. Arthritis (including ankylosing spondylitis). National. UK.

"GPs do not have a lot of knowledge or expertise when it comes to RA, and frequently simply refer patients who need help to their rheumatology team. Management of flares in the UK is haphazard, as patients need help quickly, and it is not often possible to get this."


"They don’t understand autism-spectrum disorders, referral pathways, or the impact on the extended family and main carers."

— Anonymous. Asperger. Local or regional. UK.

"There is insufficient awareness and understanding amongst many health professional of the needs and difficulties of people with an autistic-spectrum disorder—which means that patients are not dealt with sensitively or appropriately."

— Anonymous. Asperger. Local or regional. UK.

"The main problem is a lack of understanding and training in the condition we support (all autism-spectrum disorders, not just Asperger), because a fundamental aspect of the condition is communication difficulties. This is an enormous barrier to getting treatment."

— Anonymous. Asperger. Local or regional. UK.

"Healthcare professionals are often dismissive. They often don’t understand how much a debilitating condition can destroy any quality of life."


"GPs do not understand rare disorders."

— Anonymous. Blood disorders (including haemophilia, thalassaemia etc, not anaemia or cancer). International. UK.

"The young men (testicular cancer patients) are often told to go away, and come back if a lump gets bigger. This has cost many young men their lives."

— Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. National. UK.

"The doctor is not interested in anything other than the reason for the visit, and wouldn't explore any other health issues."

— Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

"Professionals do not always recognise carers’ issues."

— Anonymous. Carer/parent. Local or regional. UK.

"Lack of understanding from GPs, and over-reliance on prescription medication, rather than looking at the root cause (sticking-plaster mentality)."

— Anonymous. Carer/parent. Local or regional. UK.

"Experience of doctors not understanding their condition in depth, especially when the patients are adults."


"Many GPs do not know how to help an acoustic neuroma patient."


"Patients don’t go, because they get little support from doctors. This is due to most doctors not understanding the illness, or how it affects patients. We are 'heart sink' patients."

— Anonymous. Chronic fatigue syndrome. Local or regional. UK.

"Lack of knowledge of this health condition."

— Coeliac UK (Swindon and District). Coeliac condition. Local or regional. UK.
The doctor lacks clinical knowledge of the patient’s condition [77 references]:

“Many patients are often wrongly diagnosed with irritable bowel instead of coeliac disease.”
—Anonymous. Coeliac condition. Local or regional. UK.

“I feel that there is a very patchy understanding of the problems of coeliac disease/dermatitis herpetiformis.”

“GPs often are not expert in coeliac disease.”

“They do not know enough about coeliac condition.”
—Anonymous. Coeliac condition. Local or regional. UK.

“Some GPs seem to be less aware of the needs of coeliac patients than the patients themselves.”
—Anonymous. Coeliac condition. Local or regional. UK.

“They don’t have personal knowledge of your particular specialist condition.”

“Lack of awareness from doctors of the needs of deaf people, and the need to use registered interpreters to provide their service.”

“Many of the changes needed for diabetes (a long-term condition) involve lifestyle change. This is poorly understood by both healthcare professionals and patients.”

“They complain that the GP blames diabetes for everything.”

“GPs are usually clueless, and believe that what works for one diabetic will automatically work for all the others (which every diabetic knows is untrue). So, if it doesn’t work, they erroneously assume that you are non-compliant, and it is your fault.”

“People feel that professionals not are interested, because the person is already disabled, and does not matter. A lack of understanding of relevant social models by professionals.”
—Disability Croydon. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Doctors do not understand our particular problems.”
—Gillingham Disablement Services Centre User Group. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Disabled people often know more about their conditions than the doctor.”
—Swansea Access For Everyone Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“A lack of understanding as to what it is like to be disabled is a huge barrier. There are no disabled doctors, consultants, etc, in the medical profession. The profession has no idea of the challenges faced by our members on a daily basis.”
—Anonymous. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“People will not go to their GP if they have breathing problems. GPs don’t seem to fully understand. People with this problem are looked down upon, and assumed to be smokers.”
—Breathe Easy, Great Yarmouth and Waveney. Emphysema. Local or regional. UK.

“Theyir physician does not know about fibromyalgia, and they are not believed.”
The doctor lacks clinical knowledge of the patient’s condition [77 references]:

“Patients feel that doctors do not know enough about sickle-cell disorder, so the patients do not have confidence in their doctor.”

“Most GPs have not seen an implantable cardioverter-defibrillator (ICD) patient before. Many practice nurses do not know what an ICD is.”
—North Gloucestershire ICD Support Group. Heart disease (not stroke). Local or regional. UK.

“Specialist consultants and nurses are viewed as more knowledgeable and understanding, more patient.”
—OUR Project. HIV/AIDS. Local or regional. UK.

“The GP doesn’t have up-to-date knowledge of HIV issues.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“The first line for patients is a GP, but many patients feel that GPs have insufficient information/knowledge.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“Patients do not always disclose to their doctor, as most doctors do not understand about HIV.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“A fear that their GP does not know enough about HIV and its complexities.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“Lack of understanding and training on the needs and equality of people who are blind or partially sighted.”
—RNIB Cymru Conwy Volunteers Group. Eyesight (including glaucoma). Local or regional. UK.

“Lack of understanding of the holistic problems caused by the treatment of the condition. Patients soon lose confidence in the blinkered views and poor understanding of GPs and consultants.”

“Lack of understanding about learning disabilities, and how to communicate with people.”

“The doctor is unable to communicate with some people, due to lack of understanding of certain issues.”
—Anonymous. Mental health. Local or regional. UK.

“Doctors’ lack of insight into their condition.”

“Not being helped appropriately, due to lack of appropriate understanding of the patient’s condition or problems.”
—Anonymous. Mental health. Local or regional. UK.

“Doctors’ lack of knowledge.”
—Anonymous. Multiple sclerosis. Local or regional. UK.

“Many doctors mistakenly believe that myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a mental health, and not a neurological, disorder. ME/CFS patients have been harmed by inappropriate mental health interventions that have left them housebound or bedbound permanently.”
—Chester MESH. Neurological. Local or regional. UK.

“They visit their GP, but, on average, rate them as lacking knowledge of their condition.”
—West Berkshire Neurological Alliance. Neurological. Local or regional. UK.
The doctor lacks clinical knowledge of the patient’s condition [77 references]:

“The understanding of GPs in the UK is woefully inadequate when it comes to neurological conditions.”

“A rare illness is often not recognised by GPs, and receives late treatment.”

“Doctors sometimes give the impression that rarer cancers are irritating, as they show up their lack of knowledge; yet few seem to be prepared to do any research to enlighten themselves.”
—Anonymous. Rare cancers. Local or regional. UK.

“Lack of good training in dermatology and rheumatology (that is, only five days, in spite of psoriasis being a very common condition).”

“Down syndrome is sometimes misunderstood by doctors.”
—DSRF-UK. Rare diseases [genetic/hereditary]. International. UK.

“Lack of insight by the GP can affect the likelihood of someone seeking help.”

“GP s often have an inadequate or poor knowledge of the needs and possibilities of stroke survivors.”
—Anonymous. Stroke. Local or regional. UK.

“They worry that the GP will not have any understanding of their condition.”
—Cystitis and Overactive Bladder Foundation. Urinary (including cystitis and painful bladder). International. UK.

“Lack of expertise of GPs, consultants, and specialist nurses in how to treat an adult survivor of child abuse.”
—Aurora Health Foundation. National. UK.

“Lack of awareness and understanding around communication for not providing information in alternative formats.”
—Choices and Rights Disability Coalition (Hull and the East Riding). Local or regional. UK.

“Self-harm is better understood than ever before, but old myth and stereotyping still exist. Some members have not had good responses from healthcare officials, and are reluctant to attend accident and emergency departments or doctors for this reason.”
—H.U.S.H. Local or regional. UK.

“Disabled people are now responding to the independent-living agenda (choice and control for disabled people), but health professionals are not in line with this model, and mostly act defensively.”
—Participation Network Forum. Local or regional. UK.

“Some doctors have very little knowledge, and have not been able to offer much help in the past.”
—Prader-Willi Syndrome Association (UK). National. UK.

“A carer’s health is affected by their caring role, and the doctor is only interested in health problems, and doesn’t consider/provide direction with the issue causing the health problem. This is not useful to our carers, who are patients.”
—Anonymous. Carer/parent. Local or regional. UK.

“Doctors do not ask the right questions. The doctor does not understand a ‘caring role’.”
The GP acts as a barrier to the specialist [4 references]:

- “Lack of understanding by GPs of when to refer to a specialist.”

- “GPs seem reluctant to refer patients with a rare disease on to other professionals. So, patients become disillusioned with visits, and stop going.”
  — Behcet’s Syndrome Society. Auto immune (not scleroderma). National. UK.

- “Not being referred when necessary. GPs not adhering to referral guidelines.”
  — Breast Cancer Action Group Wolverhampton. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

- “Patients can only access a cardiac consultant through GP referral.”
  — Barnet Heartlinks. Local or regional. UK.
The patient fears a lack of confidentiality [4 references]:

“Patients don’t want anybody to see them attending the doctors.”  

“Centralised medical data, with virtually universal access to it, makes patients fearful of confiding anything that may reflect badly on them (such as a sexual disease, the effects of drinking, or a mental health problem).”  
—— Anonymous. LINks. Local or regional. UK.

“Some are reluctant to disclose their HIV-positive status to the GP. This may be because the GP sees other members of the family, and the patient is afraid that the GP will breach confidentiality, and tell other family members.”  
—— Worcester AIDS Foundation. HIV/AIDS. Local or regional. UK.

“Concerns about confidentiality.”  
—— Herts Aid. Sexual diseases. Local or regional. UK.

Different doctors give conflicting advice [2 references]:

“I hear a lot of complaints about conflicting advice between hospital and community healthcare professionals.”  
—— Anonymous. Blood disorders (including haemophilia, thalassaemia etc, not anaemia or cancer). National. UK.

“GPs’ attitude to testing varies.”  
—— PCaSO Prostate Cancer Network. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

The patient suspects that the doctor is motivated only by financial consideration [2 references]:

“Medical practitioners are governed by the UK’s National Health Service (NHS) policy, and not always by what is best for the patients (so, patients may have choose to pay for a treatment that is not available within their local or national NHS). Practitioners are financially driven.”  
—— Prostate Screening Trust. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“There are many greedy doctors who tell their patients that the treatment is too expensive (to protect their budgets), and this often puts patients off.”  
—— Anonymous. Health (general). Local or regional. UK.
3. Access to doctors

25% of patient and other health advocacy groups say that patients face difficulties in obtaining an appointment with the doctor, physically getting to the doctor, or being allowed to spend sufficient time with the doctor.
Poor access to doctors

• 9% of UK patient and health advocacy groups mention that patients are upset by only receiving short consultations
  GPs (and, to a lesser extent, specialists) function under severe time constraints. They have to attempt to meet, in an equitable way, the demands of all their many patients. They do so by strictly limiting the time they spend with each patient. A consultation time has also traditionally been seen by doctors as a useful tool for reducing patient demand: patients weary of receiving unsatisfactorily short consultation times do not see any use in making further appointments. Many of the patient groups participating in this study regard time constraints in consultations as detrimental to a doctor’s ability to deliver the correct diagnosis, treatment and care. Limited consultation time is a particular concern for patients with a rare disease, and for older people and people with a disability—all of whom need special consideration in the consultation room.

• 6% of groups feel that bureaucracy in the appointment system is detrimental to patient access to doctors
  Some of the patient groups in this study feel that bureaucracy in the appointment system can put patients off making appointments (thus comprising the patient’s clinical progress). Perhaps one of the most telling remarks comes from a carers’ group noting that the appointment system is not married to the ‘care commitments’ of patients—that it does not effectively take into account the clinical priorities of patients.

• Eight groups (3%) mention long waiting times for appointments
  • A further eight groups (3%) cite waiting times for a GP appointment as too long
  • Six groups (2%) believe that patient are unable to get appointment times to suit lifestyle considerations
  • Six carers’ groups (2%) refer to the particular problem that carers have in finding the time to see the doctor
  • Five groups (2%) note that patients have difficulties in accessing specialists (including specialist nurses)
  • One group believes that waiting times for appointments with specialists are too long
Strategies to address patients’ lack of access to doctors

The UK NHS has built its management of patient demand primarily around a system of gate-keeping and waiting times. The system made sense in the first half of the 20th century, when infectious diseases were the main ailments of the populace. Patients’ illnesses tended to be of short duration, and the numbers of visits to doctors containable. Today, however, the major burden of illness is chronic disease, requiring repeated visits to the doctor. Patient may also suffer from several chronic ailments, making their medical case even more complex. Today’s appointment system is flawed in many ways:

• The GP appointment system usually relies on the patient to be proactive in coming forward to make an appointment. The burden of deciding whether a person is in clinical need falls squarely on that person’s own shoulders.

• In the interests of fairness and equity, the GP appointment system rarely takes into account whether one patient has a more pressing medical need than another (except in life-or-death situations). NHS Direct attempted to introduce a level of triage, but only by directing patients towards self-care, to the GP, or to the hospital.

• Even when the appointment system has successfully ushered a patient into the consulting room, time remains at a premium; the doctor is always struggling to accommodate the needs of a large case list.

Much could be done to improve the appointment system. A more sophisticated or intuitive appointment system could grade the needs of individual patients—shortening waiting times for people with special needs, or factoring in an extended period in the consultation room for them. Efficient management of appointments is not an impossible task—it has long been a bread-and-butter activity for hotels, theatres, airlines, train companies, and many other service industries. The NHS appointment system needs modernisation if patients are to get appropriate treatment and care.
The patient only receives a short consultation [27 references]:

“GPs do not have the time to devote to patients with a rare disease.”

“Most patients feel hurried at appointments with GPs and consultants, who don’t have time to ask anything other than essential questions.”
—Anonymous. Blood disorders (including haemophilia, thalassaemia etc, not anaemia or cancer). International. UK.

“Time given for consultation with the GP.”
—Breast Cancer Action Group, Wolverhampton. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“When they are there, they don’t get enough time.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Lack of time during appointments.”
—Anonymous. Carer/parent. Local or regional. UK.

“Lack of time available to the doctor.”
—Anonymous. Chronic fatigue syndrome. Local or regional. UK.

“Short time available in many consultations, especially in primary care.”

“Consultation periods too short (15 minutes).”
—Disability Croydon. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“You need to rush every time you finally get an appointment.”
—Anonymous. Disability (excluding eyesight, deafness or speech). National. UK.

“Doctors do not diagnose in depth, and do not explore a patient’s symptoms.”
—Anonymous. Ex-user of psychiatric services. Local or regional. UK.

“They are rushed to get everything in 10 minutes.”

“Not enough time with the doctor.”
—Heartbeat Support Woking. Heart disease (not stroke). Local or regional. UK.

“Lack of time. They can only see the GP for a maximum of 10 minutes.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“Lack of time with the doctor.”

“Time is often a barrier, as appointment times are short.”

“Lack of time with the doctor.”
—WIN. Older people (any issues). Local or regional. UK.

“Perceived lack of time of professionals by patients.”
—Anonymous. Older people (any issues). Local or regional. UK.
The patient only receives a short consultation [27 references]:

- “Lack of time for patients to discuss their issues.”
  — Lakelands Day Care Hospice, Corby. Palliative. Local or regional. UK.

- “Lack of GP time.”

- “Patients are aware of how busy doctors are, and aren’t particularly encouraged to talk for long. Consultations are often rushed and unsatisfactory.”
  — Myeloma UK. Rare cancers. Local or regional. UK.

- “Doctors are too busy with other responsibilities.”
  — Harrow Association of Disabled People. Local or regional. UK.

- “Not enough time allocated.”

- “They need more time to speak to them, and listen to their problems.”
  — Anonymous. Local or regional. UK.

- “Getting an appointment with time to talk.”
  — Anonymous. International. UK.

- “If the GP is rushed, he/she may not be able to add up the patient’s vaguely-reported symptoms correctly.”
  — Anonymous. Local or regional. UK.

- “Doctors not having enough time.”

- “Appointment times are very short, and do not always allow time for full and frank discussions.”
  — Anonymous. Local or regional. UK.
“Difficulty in scheduling an appointment acts as a barrier to the patient [19 references]:

“Difficulty in getting appointments when they are needed.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“They can't always get an appointment.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“No flexible appointment system.”
—Anonymous. Carer/parent. Local or regional. UK.

“Appointments are not in line with care commitments.”
—Anonymous. Carer/parent. Local or regional. UK.

“Carers cannot leave the cared-for person.”
—Anonymous. Carer/parent. Local or regional. UK.

“For many, it is difficult for patients to get appointments to see their GP or consultants.”

“The appointment system is frustrating.”

“They can't always get an appointment.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Hard to get appointments.”
—Disability Croydon. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Lack of ready availability of appointments.”
—Gillingham Disablement Services Centre User Group. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Lack of available appointments.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“Secretarial support, the first port of call, sometimes seems not to be allowed to move out of a rigid system.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“Some people find it very difficult to get an appointment.”

“Lack of access to book an appointment.”
—BSL IAPT. Mental health. National. UK.

“Inability to get an appointment when needed.”
—Anonymous. Older people (any issues). Local or regional. UK.
### Difficulty in scheduling an appointment acts as a barrier to the patient [19 references]:

- “Lack of appointments.”
  — Lakelands Day Care Hospice, Corby. Palliative. Local or regional. UK.
- “Difficulty getting appointments.”
- “Cannot get an appointment.”
  — Anonymous. Thyroid deficiencies (hypo and hyper). National. UK.
- “The appointment process is not always equitable or flexible.”
  — Cardiff and Vale Coalition of Disabled People. Local or regional. UK.

### Waiting times for an appointment with the doctor are too long [8 references]:

- “Sometimes patients have too long to wait for an appointment, so they give up.”
  — Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.
- “Long waits for an appointment.”
  — Anonymous. Coeliac condition. Local or regional. UK.
- “You can’t get a quick appointment, and then they are not on time with your appointment time, and are in a rush.”
- “The length of time it takes to get an appointment to see a doctor prevents patients from seeing a doctor.”
- “Waiting time to see specific doctor, so that care is continuous, rather than having to see a different doctor each time.”
  — Anonymous. Heart disease (not stroke). UK.
- “Waiting time for appointments.”
  — Anonymous. Older people (any issues). Local or regional. UK.
- “Difficulty accessing services promptly when needed.”
  — Anonymous. Palliative. Local or regional. UK.
- “Waiting times for an appointment usually prevents clients contacting their doctor.”
  — Anonymous. Local or regional. UK.
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**Getting a correct diagnosis or balance of treatment takes too long [8 references]:**

“Diagnosis is often lengthy and traumatic.”
—Young Arthritis Support (I. W.). Arthritis (including ankylosing spondylitis). Local or regional. UK.

“People may have had symptoms for a long time before getting diagnosed with coeliac disease.”
—Coeliac UK. Coeliac condition. National. UK.

“Being wrongly diagnosed causes frustration, and patients do not often insist on a second opinion or know anything about coeliac disease. Therefore, they are often many years in pain.”
—Anonymous. Coeliac condition. Local or regional. UK.

“The average time from symptoms to diagnosis is something like 13 years.”
—Anonymous. Coeliac condition. Local or regional. UK.

“Investigative work takes too long, with delays over months to obtain results.”
—Anonymous. Ex-user of psychiatric services. Local or regional. UK.

“Inability of medics to react quickly to a non-medical emergency.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“They don’t respond early enough when we know that we are getting ill.”
—HUG. Mental health. Local or regional. UK.

“Nurses seem to want to play at diagnosis before going higher up.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

**The patient is unable to get an appointment time that suits their lifestyle [6 references]:**

“Not being able to book an appointment when they need one.”
—Edinburgh Young Carers Project. Local or regional. UK.

“No bookable appointments to allow carers to arrange alternative care for the person they care for.”

“Carers need emergency appointments due to their role, but they don’t get them.”
—Anonymous. Local or regional. UK.

“The appointment system isn’t conducive to seeing a doctor at a time that is convenient to lifestyle requirements.”
—Anonymous. Local or regional. UK.

“Surgery opening hours.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Not always able to get an appointment at a time that suits their needs.”
—Barking and Dagenham LInk. Local or regional. UK.
Carers have a particular problem in finding the time to see the doctor [6 references]:

“Patients in our speciality, ie carers, are often prevented from going to see the doctor because they don’t have time for themselves, or they can’t leave the person they care for and can’t get respite.”
—Anonymous. Carer/parent. Local or regional. UK.

“For the carers—they haven’t the time, due to their caring role.”
—Anonymous. Local or regional. UK.

“It is often difficult for carers to leave the person they care for, to get to the surgery, because their focus is on the health of the person they care for.”
—Anonymous. Carer/parent. Local or regional. UK.

“Appointment systems do not prioritise carers, so they are not always able to attend the GP at set times, due to caring for someone who needs support while they are out.”
—Anonymous. Carer/parent. Local or regional. UK.

“Carers are often unable to commit time to going to the doctor.”
—Anonymous. Carer/parent. Local or regional. UK.

“Carers may need respite care in place before they can visit their doctor.”

Specific difficulties in accessing specialists [5 references]:

“Need to be seen by consultants or specialist nurses, and appointments/access to them is not readily available.”
—Anonymous. Arthritis (including ankylosing spondylitis). Local or regional. UK.

“Lack of access to their specialist or specialist nurse.”

“Access to specialist clinics varies greatly. Most people with type-1 diabetes can get specialist hospital clinic care, but access for people with type-2 diabetes is more usually limited to GPs/practice nurses. So, many people with type-1 diabetes only use GPs/practice nurses.”

“Access to a doctor with enough relevant specialist training and time to give guidance to the patient.”
—Anonymous. Diabetes. UK.

“Many complain that they cannot see a specialist/consultant when they visit clinics.”
—Anonymous. Blood disorders (including haemophilia, thalassaemia etc, not anaemia or cancer). National. UK.
Waiting times for an appointment with the GP are too long [3 references]:

“Difficult to secure GP appointments. Often, the waits are over a week.”
—Anonymous. Older people (any issues). Local or regional. UK.

“The length of my GP’s waiting time.”
—WIN. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“A long wait for a patient to see their own physician.”
—Anonymous. Local or regional. UK.

Waiting times for appointments with specialists are too long [1 reference]:

“For follow-up appointments, there is a significant risk of delayed appointments due to limitations of capacity within the hospital system, and targets that concentrate on first referrals.”
—Anonymous. Eyesight (including glaucoma). International. UK.
4. Patients’ lack of awareness of their own clinical needs

18% of patient and other health advocacy groups say that patients may be unaware of the need to see a doctor when they should.
Lack of patients’ awareness of their own clinical needs

• 7% of UK patient and health advocacy groups say that patients may be aware of having a medical condition—but lack the knowledge needed to proceed further
  • Patients know that they have symptoms, but do not recognise these symptoms for what they are
  • Patients do not know that they should (or when they should) see the doctor
  • Patients do not understand the importance of seeing as doctor as soon as symptoms appear
  • Patients are not aware that treatments are available for their medical condition/symptoms
  • Patients do not possess information that would help them make the decision to come forward and see the doctor
  • Patients do not have access to information in user-friendly formats (easy-to-read; large print; email; Braille; audio CD, etc)

• 4% of groups say that carers are reluctant to visit the doctor because they do not look after their own health enough, and instead prioritise the interests of the person for whom they care
Some carers prefer not to believe that their own health is as important as that of the person for whom they care.

• 3% of groups say that patients may be aware of having a medical condition—but do not see any point in seeking diagnosis or treatment
Patients may not seek treatment or care if they think that no (or few) health benefits will be the result of doing so. One group specialising in coeliac disease notes that patients can become disillusioned when advice and treatment do not translate into health improvement. Patients seeking alternative therapies (such as physiotherapy) may not believe that the NHS will provide them with this resource. Some patients (especially older people) prefer to suffer in silence than go to the doctor.

• 3% of groups say that patients can be in a state of denial about their condition
Groups specialising in cancer, diabetes, eating disorders, and stroke, and carers’ groups, say that people can be tempted to deny that they have a condition if they desire to be of ‘normal’ health, or if they fear appearing to be weak.

• Three groups (1%) say that patients may not be aware of having a medical condition
An arthritis, cancer, and mental health group each point out that patients may not realise that they have symptoms, or may not link the symptoms with a medical condition.

• One group says patients may not take care of their own health
One group specialising in haematological cancers notes that some people will care for themselves as best they can rather than seek help from the doctor. (In rare circumstances, the opposite may happen—a patient may prefer the drama of being ill, and relish the attention it brings.)
Strategies to address patients’ lack of awareness

- Patients need to understand the importance of self-care, and to be alert to the health of their own bodies. If parents or carers, they should not sacrifice their personal health while looking after that of other people’s.

- Patients and the public should be better informed about the importance of early intervention, and given information (in easy-to-understand language) about the types of symptoms that might indicate a need to see the doctor.

- Doctors could be more open-minded about prescribing alternative forms of treatment to medication (such as physiotherapy).
The patient is aware of having a medical condition—but lacks knowledge (or information in patient-accessible formats) about how to proceed further [22 references]:

“Patients lack of understanding and knowledge of their condition. They lack understanding of when to see their doctor.”

“Not understanding the need to see the GP.”
—Anonymous. Asperger. Local or regional. UK.

“Lack of knowledge.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Ignorance of early presentation to medical staff.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Diabetes is quite a complex condition. Many patients don’t realise how dangerous it is.”

“Uncertainty about who to see (specialist or GP) causes difficulties.”
—Anonymous. HIV/AIDS. Local or regional. UK.

“Patients' lack of awareness of treatment options.”
—Anonymous. Mental health. Local or regional. UK.

“Lack of knowledge of existing services and their remit.”
—Anonymous. Mental health. Local or regional. UK.

“Lack of understanding by patients of when and how to access doctors.”

“Lack of knowledge about the condition.”

“Patients do not recognise the symptoms.”
—Anonymous. Local or regional. UK.

“They could be vague about their symptoms (and those are many and varied).”
—Anonymous. Local or regional. UK.

“They do not always recognise the serious nature of their symptoms.”

“People with the symptoms of arthritis (pain, immobility and loss of range of movement in joints) do not know that there is a lot they can do to prevent their condition from worsening.”
The patient is aware of having a medical condition—but lacks knowledge (or information in patient-accessible formats) about how to proceed further (22 references):

“Lack of information and advice from doctors on where to go to (our group tries to provide this, but, due to limited funding, we are restricted in our ability to do so).”
—Warrington Disability Partnership. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Lack of information in accessible formats, such as large print, audio CD, or braille.”
—RNIB Cymru, Conwy Volunteers Group. Eyesight (including glaucoma). Local or regional. UK.

“Lack of accessible information—braille, large print, audio, email—for appointment letters.”
—Anonymous. Eyesight (including glaucoma). Local or regional. UK.

“Advice is minimal, so patients often have no faith in their GPs’ ability to help them.”
—Fibromyalgia Support for Surrey and Sussex. Fibromyalgia. Local or regional. UK.

“Lack of easy-read materials for certain subjects.”
—Anonymous. Mental health. Local or regional. UK.

“Inadequate information given to patients on their condition.”

“Not providing information in alternative formats.”
—Choices and Rights Disability Coalition (Hull and the East Riding). Local or regional. UK.

“Written information not being available in accessible formats for visually-impaired people.”
—Anonymous. Local or regional. UK.
A category of patients who may not take care of their own health—carers [13 references]:

“We support family carers, and it has been found that carers are more likely to neglect their own health, and prioritise the health of the person they care for over theirs.”
—Carers Centre Hull. Carer/parent. Local or regional. UK.

“Carers often neglect own health when looking after a relative, so delay going to seek help.”
—Anonymous. Carer/parent. Local or regional. UK.

“I support carers. They neglect their own needs because their focus is on the health of the person they care for.”
—Anonymous. Carer/parent. Local or regional. UK.

“Patients in our speciality, i.e. carers, are often prevented from going to see the doctor because they don’t realise that their health is as important as that of the cared-for person.”
—Anonymous. Carer/parent. Local or regional. UK.

“Carers put their own health needs second to those of the person they provide care for.”
—Anonymous. Carer/parent. Local or regional. UK.

“We represent unpaid carers, and their caring responsibilities often prevent them from looking after their own health. Yet their health is imperative, because of what they do.”
—Anonymous. Carer/parent. Local or regional. UK.

“Carers tend to focus on the health of the cared-for person and not their own health. Carers do not wish to be seen as not coping.”
—Anonymous. Carer/parent. Local or regional. UK.

“Often, carers are too involved in what their cared-for are going through, to seek help for themselves.”
—Anonymous. Health (general). Local or regional. UK.

“My organisation supports the carers of people with health or disability issues. For the carers themselves, they tend to put the needs of the cared-for before their own.”

“Carers tend to neglect their health.”
—Anonymous. Local or regional. UK.

“Carers find it difficult to consider their own needs when they are caring for someone.”
—Anonymous. Local or regional. UK.

“Lack of opportunity to care for their own health.”
—Anonymous. Carer/parent. Local or regional. UK.

“Carers are unwilling or unlikely to complain about their health, as they fear for the treatment of those for whom they care.”
—Suffolk Family Carers Carer/parent. Local or regional. UK.
The patient is aware of having a medical condition—but does not see any point in seeking diagnosis or treatment [9 references]:

“For some patients, symptoms are vague, and they can become dispirited when advice/treatments do not translate into improvements in their health.”
—Anonymous. Coeliac condition. Local or regional. UK.

“Some patients do not attend specialist clinics because they do not see the need (e.g. audit clinics).”

“I find that, often, people do not want to take any more drugs, but would welcome more access to physiotherapy and podiatry.”
—Anonymous. Local or regional. UK.

“Pessimism about being able to secure appropriate treatment.”
—Bright. Mental health. National. UK.

“Don’t think they can help anyway.”
—HUG. Mental health. Local or regional. UK.

“There is nothing the doctors can do, so patients just go away.”
—Anonymous. Multiple sclerosis. Local or regional. UK.

“Perceived ineffectiveness of treatments.”
—Anonymous. Mental health. Local or regional. UK.

“Many older people suffer, rather than go to GPs, who they cannot understand.”
—Anonymous. Older people (any issues). Local or regional. UK.

“They think that nothing can be done about their problem.”
The patient is in a state of denial about their condition [8 references]:

“Denial.”

“If they are reassured, that is what they want to hear. If they feel something is wrong, they do not persist.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“People with eating disorders can be reluctant to acknowledge that they have a problem, and be slow to seek help when they do. They can feel that they are not deserving of receiving treatment, or would not be believed or understood if they did seek help.”

“Sometimes, the patient does not want to admit that there is a health problem.”
—Stratford upon Avon Stroke Support Group, UK Stroke. Local or regional. UK.

“Don't accept that they have a problem.”
—Anonymous. Local or regional. UK.

“Wanting to be normal.”

“Feeling inadequate, that they 'should' be able to cope.”
—Anonymous. Carer/parent. Local or regional. UK.

“Fear of giving up, or appearing weak.”
—Anonymous. Carer/parent. Local or regional. UK.

The patient is not aware of having a medical condition [3 references]:

“Lack of awareness about arthritis by the patient (who might not be aware they have arthritis or the need to see a doctor),”
—Arthritis Care. Arthritis (including ankylosing spondylitis). National. UK.

“Many of our patients were unaware that the symptoms they had were connected to a medical condition.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“We are not aware we are ill.”
—HUG. Mental health. Local or regional. UK.

The patient may not take care of their own health [1 reference]:

“There are a few among us who feel that it is more dramatic to be gravely ill than to take reasonable care of themselves (though not many, thankfully).”
5. Poor doctor-patient relationships

17% of patient and other health advocacy groups think that poor doctor-patient relationships act as a barrier to patients seeking help from the doctor when they should.
Three key reasons for poor doctor-patient relationships

• **9% of UK patient and health advocacy groups say that patients can be so submissive to their doctor that they may be reluctant to visit the doctor**

An overly submissive attitude to the doctor can be present in patients who have almost any type of chronic disease or disability, including arthritis, cancer, coeliac disease, diabetes, heart disease, learning difficulties, mental health, and stroke. Older people are particularly prone to displays of extreme respect for doctors, having been brought up by generations who, in turn, had been taught not to bother or worry doctors unnecessarily. Some patients prefer not to challenge their doctors, in case the repercussion affects their access to treatment. Others find the doctor so patronising that they are unable to deal with the situation.

• **6% of groups say that patients are put off by the poor communicational skills of the doctor**

Problems here may include:

- The patient has difficulty articulating needs, or in understanding what is being said.
- Doctors do not communicate in lay terms, or engage the young, the old, or patients with a communication disability.
- Doctors are not good at conveying the risks and benefits of healthcare choices.
- Two mental health groups point out that the patient may not go to the doctor for fear that they will not be able to refuse any undesired medication prescribed to them.

• **One group mentions that a lack of continuity of care—patients not always being able to see the same doctor—hinders patients from accessing the healthcare system**
Strategies to overcome poor doctor-patient relationships

• Patients need more training in how to hold ‘honest’ conversations with their doctor.

• Doctors need training in how to listen and communicate with patients from all walks of life.

• More research needs to be carried out into how doctors can convey the relative risks and benefits of treatment in simple, lay terms.
I. Patients are too submissive to doctors

*The patient does not want to bother the doctor [12 references]:*

“Arthritis has no cure, so many older patients self-medicate, rather than bother their doctor.”
—Gloucestershire Arthritis Trust. Arthritis (including ankylosing spondylitis). Local or regional. UK.

“They tend to think they will be brushed aside, or are bothering their doctor.”
—Anonymous. Blood disorders (including haemophilia, thalassaemia etc, not anaemia or cancer). National. UK.

“They may have had a previous diagnosis of irritable bowel syndrome (IBS), and may not feel confident about approaching the doctor about ongoing symptoms if a diagnosis has already been made.”
—Coeliac UK. Coeliac condition. National. UK.

“When a doctor says to you that it is ridiculous for him to be prescribing food as a medicine, it puts you off going to him. You feel second rate, a nuisance, and that you are wasting his time.”
—South Wilts Coeliacs. Coeliac condition. Local or regional. UK.

“Our age demographic is the over-65s, who were brought up ‘not to bother the doctor’.”

“Some patients don’t like to bother their GP.”
—Anonymous. Older people (any issues). Local or regional. UK.

“They don’t want to bother the busy doctors.”
—Stratford upon Avon Stroke Support Group, UK Stroke. Local or regional. UK.

“They don’t want to bother the GP.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“The patients don’t want to ‘bother’ the doctor.”
—Anonymous. Older people (any issues). Local or regional. UK.

“Patients do not want to bother the doctor.”
—Anonymous. Local or regional. UK.

“People tend not to want to bother their doctor.”

“Don’t want to worry the doctor.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.
The patient feels overawed by the doctor, who can be patronising or patriarchal [10 references]:

“Consultants are men. Patients are in awe of consultants, and feel that, if challenged, the consultants would be resentful, and this might affect their treatment.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“They feel patronised, judged and criticised for not always achieving the targets set for the management of their diabetes, despite the fact that they are usually trying their best.”

“Some doctors have a patronising view of disabled people.”
—Swansea Access For Everyone. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Domineering physicians with an ‘I know best’ attitude.”
—Anonymous. Learning difficulties (including autism). Local or regional. UK.

“Doctors are patronising.”
—Anonymous. Multiple sclerosis. Local or regional. UK.

“Fear of being patronised.”
—Aurora Health Foundation. National. UK.

“Many patients see the doctor being in control of their condition, not the patient themselves.”

“Some medical professionals can demonstrate an ageist view/attitude, and therefore can patronise older patients, thus preventing the patient from wishing to discuss openly symptoms which they must.”
—Huddersfield Heartline Support Group. Heart disease (not stroke). Local or regional. UK.

“Doctors seem to only hear their own voices, and assume that they know best.”
—Anonymous. Mental health. Local or regional. UK.

“They feel that they will be patronised and talked down to. They feel normal-life events and reactions can be pathologised and made into symptoms.”
—Consultation and Advocacy Promotion Service. Local or regional. UK.
I. Patients are too submissive to doctors

The patient does not want to waste the doctor’s time [6 references]:

“Not wanting to feel that you are wasting the doctor’s time.”
—WIN. Older people (any issues). Local or regional. UK.

“They sometimes feel that they would be wasting the doctor’s time, and would prefer to speak to a specialist nurse.”
—East Lindsey Heart Support Group Heart disease (not stroke). Local or regional. UK.

“People don’t want to waste the doctor’s time, as they see them as being very busy”

“They often feel that they could be wasting the doctor’s time”
—Anonymous. Stroke. Local or regional. UK.

“Patients are afraid that they will be ‘wasting’ the doctor’s time with something that may turn out to be a false alarm.”
—Anonymous. Local or regional. UK.

“Wasting valuable doctor time.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.
## Poor doctor-patient communication

**The doctor lacks communication skills [9 references]:**

- "Lack of awareness of how to communicate with people who have aphasia."
  — Speakeasy. Aphasia. Local or regional. UK.

- "Doctors need to recognise and understand how to support people with aphasia, allowing time and taking a person-centred approach."

- "Not understanding what you are being told by the doctor."
  — WIN. Older people (any issues). Local or regional. UK.

- "We have many foreign doctors who cannot speak good English."
  — Anonymous. Older people (any issues). Local or regional. UK.

- "Lack of communication skills (especially listening skills) among professionals."
  — Anonymous. Older people (any issues). Local or regional. UK.

- "Doctors don’t always talk in lay terms, or explain things properly."
  — Barking and Dagenham LINk. Local or regional. UK.

- "Not understanding the risks and benefits of the medicines, so not being able to have an honest conversation."

- "Feedback from carers is that the consultant talks to the computer not the patient."
  — Anonymous. Local or regional. UK.

- "Research has shown that a great many teenagers and young adults who are developing cancer often delay visiting their doctor when they are aware of a problem due to the fact that their doctor doesn’t know how to communicate."
II. Poor doctor–patient communication

The doctor is particularly poor at communicating with patients who have a communication disability [6 references]:

“Lack of communication with them, ie diagnosing without an interpreter present, writing notes to communicate, not realising that there is high illiteracy on deaf society.”

“Unable to understand their doctors if the practice refused to provide an interpreter.”
—deafPLUS. Deafness. Local or regional. UK.

“Usually, lack of communication tactics by the doctor, such as not facing the patient, talking to another because its easier and quicker, having appointment systems that only use the phone, and, therefore, exclude some. Not using professional interpreters for British sign language (BSL) users.”
—Anonymous. Deafness. Local or regional. UK.

“Lack of British Sign Language interpreter support if the patient does manage to book an appointment.”
—BSL IAPT. Mental health. National. UK.

“Communication difficulties: British sign language (BSL) interpreters not being available for appointments.”
—Anonymous. Local or regional. UK.

“Doctors will ignore requests for face-to-face communication, turning away to the computer screen, etc, so that the hearing-impaired ‘patient’ does not always get the information.”
—Anonymous. Local or regional. UK.

The patient fears being denied informed consent [2 references]:

“Threat of being put onto mind-altering medication.”
—People’s Forum, The. Mental health. Local or regional. UK.

“Fear of being forced into treatment.”
—Anonymous. Mental health. Local or regional. UK.
II. Poor doctor-patient communication

*Being honest with the doctor is impossible—whatever the reason [2 references]*:

“You cannot be honest with doctors.”
—Anonymous. Mental health. Local or regional. UK.

“Honest talking may be limited by the structure.”

*The patient has a poor relationship with the doctor [1 reference]*:

“If we don’t get on well with them.”
—HUG. Mental health. Local or regional. UK.
III. Lack of continuity of care

The patient is not permitted to see the same doctor [6 references]:

“They do not get access to see the same GP.”

“Never seeing the same doctor.”
—Heartbeat Support Woking. Heart disease (not stroke). Local or regional. UK.

“Lack of continuity seeing their regular doctor.”
—Sunderland Cardiac Support Group. Heart disease (not stroke). Local or regional. UK.

“Not always seeing the same GP.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“Patients are more likely to see the same staff at the specialist clinic, and their needs met.”
—OUR Project. HIV/AIDS. Local or regional. UK.

“Not always seeing their own GP, so a lack of continuity.”
6. Psychological or cultural barriers

10% of patient and other health advocacy groups state that psychological or cultural barriers prevent patients from seeing the doctor when they should.
Seven reasons for psychological and cultural impediments to seeing the doctor

• 3% of UK patient and health advocacy groups say that language and cultural barriers inhibit patients from going to the doctor
  When either the patient or the doctor does not have English as a first language, good communication may become harder, and the NHS does not have ready access to interpreters and translators. A group representing the interests of people who are deaf notes that doctors are rarely able to provide translations of their comments in British Sign Language (BSL).

• 2% of groups believe that men are particularly reluctant to visit the doctor
  One diabetes group and six prostate cancer groups emphasise that men may be slow to seek the attention of doctors, and are particularly unwilling to discuss ‘intimate’ symptoms.

• Five groups (1.6%) say that patients can be afraid to admit failings in compliance
  The groups indicate that such an issue is psychological; patients do not want to lose face in front of the doctor by being forced to admit failings in adherence to a drug regimen (even though they know that being forthcoming may be better for their own health). Patients also do not want to feel that they have let down the doctor.

• Three groups (1%) believe that patients may lack the confidence to go (or relate) to the doctor
  A teenage cancer group points out that young people are especially likely to lack the confidence to talk honestly with, or challenge, the doctor (and they may not also want to take their parents along).

• Three groups (1%) say that people may not like to go to the doctor
  The groups observe that patients may not know their doctor well, may lack confidence in the doctor, or may find the whole experience of accessing healthcare to be stressful.

• Three groups (1%) say that a patient’s carers may lack understanding or communicational skills
  Two children’s groups (one eczema, one Down’s syndrome) say that overworked parents may not know when their children need to attend the doctor. A carers’ organisation maintains that a patient’s reliance on a carer to know when the patient should go to the doctor can hinder that patient’s access to the doctor.

• Two groups (0.6%) believe that family considerations may inhibit patients from going to the doctor
  A cancer group says that patients may avoid going to the doctor because they do not want their family circumstances disrupted. A stroke group argues that a spouse may dissuade a patient from going to the doctor.
Strategies to overcome the psychological and cultural impediments to seeing a doctor

• Cultural barriers that hinder patients from going to see a doctor when they should are among the hardest to surmount. Education in the community, perhaps delivered by health NGOs, could help. Investment in more translators and British Sign Language (BSL) interpreters should be more of a straightforward matter.
Language and cultural barriers inhibit the patient from going to the doctor [9 references]:

“Language barriers.”
—Anonymous. Mental health. Local or regional. UK.

“Many have language barriers. The older, sometimes hard-of-hearing patients feel that they are being rude if they keep saying ‘pardon’ to a doctor whose first language is not English.”
—Anonymous. Diabetes. Local or regional. UK.

“Our patients face the language barrier—they cannot express what they feel to their doctor.”
—Innovative Vision Organisation. HIV/AIDS. Local or regional. UK.

“Lack of linguistic support (interpreters and translation) by doctors.”
—Anonymous. Mental health. Local or regional. UK.

“Lack of doctors’ understanding around cultural issues. Language barrier. Lack of trust.”
—African and Caribbean Mental Health Services. Mental health. Local or regional. UK.

“Cultural factors.”
—Age UK, Cheshire. Older people (any issues). Local or regional. UK.

“Lack of understanding by the GP of the cultural needs of deaf British Sign Language patients.”
—BSL IAPT. Mental health. National. UK.

“Lack of cultural awareness by doctors. Cultural inappropriateness of some interventions.”
—Anonymous. Mental health. Local or regional. UK.

“Self-esteem issues prevent the patient from feeling that they are entitled to help and support.”
Men are particularly reluctant to visit the doctor [7 references]:

“Men are often reluctant to see their GP.”
—PCaSO Prostate Cancer Network. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Reluctance of men to visit doctors, or discuss intimate symptoms.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Men are known to be reluctant to visit GPs.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. National. UK.

“We find that men are not so proactive about their health as women, and are reluctant to see a doctor for this reason. Men can be embarrassed about talking to doctors, as the disease affects a ‘private’ part of the body, the penis.”
—Prostate Project. Local or regional. UK.

“Men are reluctant to visit the doctor.”
—Wiltshire Involvement Network. Local or regional. UK.

“Irrespective of ‘specialty’, male patients have historically been slow to seek advice from their GPs.”
—Anonymous. Patient and public involvement network. Local or regional. UK.

“Men have a reputation for not going to see their doctor—particularly with prostate problems—and may be embarrassed to do so. They may have heard about the digital rectal examination (DRE), and wish to avoid it.”
—Anonymous. Prostate cancer support group. Local or regional. UK.
The patient is afraid to admit failings in compliance [5 references]:

“Not sticking to the agreed plan, and then loss of face when admitting that.”
—Anonymous. Asthma (including COPD). National. UK.

“Not taking their medicines—they may fear the opprobrium of their doctor.”

“Some people feel that they cannot admit to varying the way they take their medication, even when they know it is better for them to admit to doing so.”
—Anonymous. Disability (excluding eyesight, deafness or speech). National. UK.

“Fear of being ‘told off’ for not following guidance.”
—Anonymous. Mental health. Local or regional. UK.

“The patient lacks the confidence to go (or relate) to the doctor [4 references]:

“Reluctance to make a fuss.”
—Anonymous. Cancer (with life expectancy of less than five years), excluding rare cancers. Local or regional. UK.

“Not talking honestly is due to lack of confidence.”
—Anonymous. Stroke. Local or regional. UK.

“Not feeling brave enough to challenge the doctor.”
—Anonymous. Asthma (including COPD). National. UK.

“Teenagers and young people with cancer often wait too long before going to the doctor, because they are nervous about going on their own (often for the first time), and they frequently don’t want to go with their parents.”
—Anonymous. Rare cancers. National. UK.
People do not like to go to the doctor [3 references]:

“Patients may not know, or have confidence in, their GP(s) and consultant.”
—Barnet Heartlinks. Local or regional. UK.

“Patients don’t usually know their GP well enough.”
—Barnet LINk. Local or regional. UK.

“But a pleasant experience—stressful.”
—Barnet LINk. Local or regional. UK.

The patient’s carers may lack understanding or communicational skills [3 references]:

“Carers are often overwhelmed with the struggle of coping with a young child, and, possibly, eczema is unfamiliar to them. Patients and carers do not know what they should expect from the doctor to manage their condition.”

“Many caregivers and parents don’t understand Down syndrome as a medical condition, or that many problems can be treated. This is not well understood by parents.”
—DSRF-UK. Rare diseases (genetic/hereditary). International. UK.

“Patients are very much dependent on their carers (who we are, and who we represent) for their access to doctors. This could be a barrier, as well as a benefit.”
—Anonymous. Carers. Local or regional. UK.

Family considerations may inhibit the patient from going to the doctor [2 references]:

“The patient does not want to disrupt the family.”
—Anonymous. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“Their spouse influences them.”
—Stratford upon Avon Stroke Support Group, UK Stroke. Local or regional. UK.
7. Difficulties faced by patients in physically getting to a doctor

10% of patient and other health advocacy groups describe the difficulties faced by patients in getting to the doctor as a barrier to seeking medical help.
Physical barriers in getting to, or being with, the doctor

A person’s medical condition may prohibit them, or frighten them, from travelling to an appointment with the doctor’s appointment (for example, if symptoms are unpredictable, or if the person has a communication disability). Seven disability groups mention the problems of physical access to GP surgeries. Travel can also be a problem, and has an inherent cost that might be too high for the patient to afford. The process of making an appointment is virtually impossible without access to a telephone. Receptionists can be intimidating and frighten a patient away. Those who have to take time off work or school may find it tough to negotiate suitable appointments with the doctor.

- 3% of UK patient and health advocacy groups say that patients’ own health problems may make visiting the doctor difficult
- 2% of groups believe that gaining entry into healthcare infrastructure is difficult for people with a disability
- 2% of groups say that patients’ transport problems may make visiting the doctor difficult
- Two groups (0.6%) say that the mechanisms involved in booking an appointment make visiting the doctor difficult
- Two groups (0.6%) say that patients may lack the time to visit the doctor
- One group (0.3 %) says that patients in rural areas find travel to the doctor particularly difficult
- One group (0.3 %) argues that the doctor’s distance from the patient may make visiting the doctor difficult
- One group (0.3 %) says that the cost of travel to the doctor may make visiting the doctor difficult
- One group (0.3 %) believes that a doctor’s secretarial/booking staff may act as a barrier to the patient
- One group (0.3 %) believes that the doctor may not be not willing to see younger patients without a parent being present in the consulting room
Strategies to overcome the physical barriers in getting to the doctor

- Improving transport facilities and ease of physical access to a doctor’s premises comes with a hefty price tag. But medical buildings should, by law, provide physical access to people with a disability. The booking process could be simplified by enabling patients (particularly people with a communication difficulty) to book appointments by email if they wish. Some doctors (not many, unfortunately) permit patients to schedule appointments outside of office working hours. Above all, healthcare staff should be cognisant of the personal efforts involved when patients need to travel to, and access, a doctor’s premises.
The patient’s own health problems may make visiting the doctor difficult [7 references]:

“Impairment of social skills, therefore not able to cope with visiting the GP, etc.”
—Anonymous. Asperger. Local or regional. UK.

“Too ill to go.”
—HUG. Mental health. Local or regional. UK.

“Complex nature of illness, and unpredictability of feeling well or ill.”
—Anonymous. Palliative. Local or regional. UK.

“Communication disability is a barrier. For those with aphasia, it is often just too difficult.”

“Often, people will not go to the GP, as they find it hard to talk openly about the condition.”
—York Carers Forum. Carer/parent. Local or regional. UK.

“The nature of a life-limiting illness can be difficult to discuss.”
—Anonymous. Palliative. Local or regional. UK.

“Paruresis was once thought to be a secret phobia, and people with this condition are unwilling to talk about it. Workshops help them overcome this problem.”
—UKPT. Urinary (including cystitis and painful bladder). National. UK.
Gaining entry into healthcare infrastructure is difficult for people with a disability [7 references]:

“Some patients experience problems accessing GP surgeries due to mobility restrictions.”
—Brighton and Hove Federation of Disabled People. Local or regional. UK.

“Physical access to surgeries.”
—Choices and Rights Disability Coalition (Hull and the East Riding). Local or regional. UK.

“Access needs are not being met if disabled.”
—Harrow Association of Disabled People. Local or regional. UK.

“Many patients are still physically unable to access surgeries and hospitals because of lack of disabled (or mis-used) car parking, or a lack of disability-accessible doors.”
—Brecknock Access Group. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Insufficient disabled parking near hospitals, doctors’ surgeries, etc.”
—Disabled Motorists Federation. Disability (excluding eyesight, deafness or speech). National. UK.

“Lack of full physical access.”
—Swansea Access For Everyone. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“There are still too many barriers—not just physical barriers—that can deter disabled people from accessing medical services.”
—Anonymous. Disability (excluding eyesight, deafness or speech). National. UK.
The patient’s transport problems may make visiting the doctor difficult [5 references]:

“There are practical barriers such as travel, parking.”

“Their lack of mobility.”
—Gwent Disabled Motorists Club. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

“Transport. Travel is a huge issue for vision-impaired people.”
—Anonymous. Eyesight (including glaucoma). Local or regional. UK.

“Transport issues for older people.”
—Anonymous. Older people (any issues). Local or regional. UK.

“Transport. Need assistance.”
—Anonymous. Stroke. UK.

The physical mechanisms involved in booking an appointment may make visiting the doctor difficult [4 references]:

“Difficulty in basic telephone access.”
—Anonymous. Local or regional. UK.

“Automated appointment systems at GP surgeries cannot be seen, and so appointments are missed. Lack of accessible information—braille, large print, audio, email—for appointment letters.”
—Anonymous. Eyesight (including glaucoma). Local or regional. UK.

“Being profoundly deaf means that you cannot ring the doctor for an appointment in the same way a hearing person can. You may rely on friends or family members (which may not be suitable for confidential situations). You may be lucky and have email or text access.”

“Some GPs have appointment systems that are unsatisfactory and difficult, involving phoning at specified times.”
—Anonymous. Coeliac condition. Local or regional. UK.

The patient lacks the time to visit the doctor [2 references]:

“Practical barriers include time off work and school.”

“You normally have to book time off work due to surgery open hours.”
—Anonymous. Disability (excluding eyesight, deafness or speech). National. UK.
Patients in rural areas find travel to the doctor particularly difficult [2 references]:

“The physical difficulty of getting to a doctor from a very rural area.”
—Anonymous. Older people (any issues). Local or regional. UK.

“Rural county: transport problems.”
—Wiltshire Involvement Network. Local or regional. UK.

The doctor’s distance from the patient may make visiting the doctor difficult [1 reference]:

“Transport, distance to GP practice.”
—Anonymous. Palliative. Local or regional. UK.

The cost of travel to the doctor may make visiting the doctor difficult [1 reference]:

“Cost can be a factor, even in the UK, if the patient is destitute, or is in the (UK) asylum system, and some hospitals refuse to pay the patient’s travel costs.”
—Anonymous. HIV/AIDS. Local or regional. UK.

The facility’s secretarial/booking staff act as a barrier to the patient [1 reference]:

“Receptionists who are the initial contact at doctors’ surgeries are rude, misinformed, and impatient, making it hard to disclose status.”
—Terrence Higgins Trust. HIV/AIDS. National. UK.

The doctor is not willing to see a younger patient [1 reference]:

“GPs will rarely see a young person (unaccompanied by an adult).”
—Anonymous. Rare cancers. National. UK.
8. The doctor does not meet patients’ needs

5% of patient and other health advocacy groups believe that a doctor’s failure to meet patient expectations acts as barrier to patients seeking help from the doctor when they should.
Why doctors do not meet patients’ needs

• **3% of UK patient and health advocacy groups note that the patient may have a condition which is not medically recognised or accepted**

Patients who may struggle to convince a doctor that they are ill could have any one of a wide variety of diseases, including: ADHD; arthritis; allergies; asthma and other respiratory problems; chronic fatigue syndrome; fibromyalgia; heart disease; and rare diseases. Not surprisingly, when faced with disbelief or inaction from a doctor, patients may not always seek further help from the doctor when they need to do.

• **Four groups (2%) say that the patient may not go to the doctor if the doctor does not prescribe treatment the patient wishes**

An arthritis group says that older patients seeking relief from arthritis may be frustrated by doctors who merely attribute suffering to the inevitable process of ageing. A tinnitus group also laments the situation in which doctors can become resigned to doing nothing on behalf of their patients. A breast cancer group refers to doctors who are not willing to explore other options on behalf of their patients. A patient belonging to a mental health group notes an inability to be prescribed alternative, non-drug therapy.

• **Two groups (0.6%) say that the doctor may ignore the efforts a carer makes on behalf of the patient**

One group says that carers are often not engaged or included by doctors in conversations. A group specialising in cancer in children and young people says that carers may have to contend with inaction on the part of doctors.
Strategies to help doctors better meet patients’ needs

• Patients sometimes have grand expectations for their health, and doctors need to manage unreasonable demands. However, high levels of undiagnosed disease in the UK population do suggest that circumstances in which patients fail to be given the correct or appropriate treatment and care may be surprisingly common. Patients today are often far more knowledgeable about their health and symptoms than patients in the past, and well able to contribute when doctors try to provide them with the best medical outcome. Doctors might therefore be well advised to offer patients the chance to express themselves more freely in the consultation room.
The patient has a condition that is not medically recognised or accepted [10 references]:

“ADHD is still a disorder that not everyone believes in.”
—ADD-Lib. ADHD/ADD. Local/regional. UK.

“Arthritis is an ignored medical condition; nothing is done to help. Arthritis is the one medical condition less talked about than any other.”
—Arthritis Care. Arthritis (including ankylosing spondylitis). National. UK.

“GPs do not consider arthritis to be a condition that needs 'treating.'”

“The UK’s National Institute of Health and Clinical Excellence (NICE) does not recognise the research which proves that people with viral myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS) require anti-viral drugs to improve their health.”
—Anonymous. Chronic fatigue syndrome. Local or regional. UK.

“Many doctors do not acknowledge the existence of fibromyalgia, and most do not know how to treat it.”
—Fibromyalgia Support for Surrey and Sussex. Fibromyalgia. Local or regional. UK.

“Medical professionals fail to recognise the disease. They believe it to be something that it is not—and the patient is left having to educate the medical professionals, left to defend and self diagnose themselves, with the professionals ignoring all.”
—Sarcoidosis Awareness Society. Auto immune (not scleroderma). National. UK.

“Allergic illness has no (or only a fractional) place in medical training. Which means that many GPs are unable or unwilling to consider it as the possible cause of symptoms presented.”
—Action Against Allergy. Allergy (including hayfever). National. UK.

“Being disbelieved, or dismissed as anxious, or as having trivial worries—underestimation of the condition and its impact.”
—Anonymous. Asthma (including COPD). National. UK.

“Sometimes, denial of their condition.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.

“Feeling that the doctor does not take their symptoms seriously.”
—Anonymous. Heart disease (not stroke). Local or regional. UK.
The doctor does not prescribe the treatment that the patient wishes [4 references]:

“Fobbed off with: “It’s to be expected”, or “It’s your age, there is nothing we can do.” “

“Going back to the doctor, and just getting the same answer.”
—Breast Cancer Action Group Wolverhampton. Cancer (with life expectancy of five years or more), excluding rare cancers. Local or regional. UK.

“As a patient, I am not very keen on taking medication. I would prefer a talking therapy.”
—Anonymous. Depression. Local or regional. UK.

“Many GPs say that there is no cure for tinnitus, and the patient is told to go away and live with it.”
—Birmingham and District Tinnitus Group. Local or regional. UK.

The doctor ignores the needs of the patient or carer [2 references]:

“Carers report that GPs do not generally discuss their caring role, or offer extra support.”
—Anonymous. Carer/parent. Local or regional. UK.

“Being fobbed off with explanations, such as ‘growing pains’. Not being given choices.”
9. Shortage of resources in the NHS

2% of patient and other health advocacy groups believe that shortfalls in NHS resources prevent patients from seeing the doctor when they should.
Shortage of resources in the NHS

• 1% of UK patient and health advocacy groups think that a lack of investment in the healthcare system hinders patients from coming forward for the care they need
  Groups refer to a lack of NHS financial resources, and ‘postcode lotteries’ that lead to inequities in care.

• Three groups (1%) point to shortages in specialists and GPs as a reason why patients do not seek help from doctors when they should
Strategies to address shortages of resources

- Healthcare is such a large part of the UK’s national GDP that cutbacks in the NHS can only be expected whenever the country experiences an economic downturn. As we read in this report, people not coming forward to seek help from their doctor when they should is likely to only add to the cost burden of UK healthcare. Cost savings could be made by working to eliminate many of the factors that inhibit people from coming forward for the care and treatment they need.
The healthcare system lacks resources [3 references]:

“Patients feel frequently ignored, and involved in the financial postcode lottery.”
—Young Arthritis Support (I. W.). Arthritis (including ankylosing spondylitis). Local or regional. UK.

“The majority of our members are housebound, some are bedbound, and they find it difficult to have domiciliary visits.”

“The doctors have cut back in some areas how many gluten-free products we can have on prescription, making it especially harder for newly-diagnosed coeliacs.”
—Wirral Group of Coeliac UK. Coeliac condition. Local or regional. UK.

Lack of specialists [1 reference]:

“There are too few stroke specialists.”
—Anonymous. Stroke. Local or regional. UK.

Lack of both primary-care doctors and specialists [1 reference]:

“Lack of doctors.”
—Down Syndrome Training and Support Service Ltd. Disability (excluding eyesight, deafness or speech). Local or regional. UK.

Lack of primary-care doctors [1 reference]:

“Poor local services, with inappropriate number of physicians in post.”
—Young Arthritis Support (I. W.). Arthritis (including ankylosing spondylitis). Local or regional. UK.
Appendix

76 reasons why patients do not see their doctor when they should
Appendix I: Profile of UK groups

Specialty of UK respondent patient groups  % of responses
Total number of patient groups = 316

Mental health 12.5%
Cancer 9.3%
Disability 8.9%
Carer/parent 8.6%
Heart disease 7.4%
Arthritis 6.8%
HIV/AIDS 6.6%
Neurological 6%
Stroke 5.1%
Older people 4.7%
Diabetes 4.3%
Gastrointestinal 3.9%
Rare diseases 2.3%
Urinary 1.6%
Congenital 1.6%
Respiratory 1.6%
Haematological 1.2%
Auto-immune 1.2%
Heart disease 0.8%
Allergy 0.8%
Other chronic disease 0.8%
Health (general) 0.8%
Learning difficulties 0.8%
Palliative 0.8%
Sexual diseases 0.8%
Endocrine 0.8%
Skin conditions 0.8%
Kidney 0.4%

Geographic remit of UK respondent patient groups  % of responses
Total number of patient groups = 316

Local or regional within a single country 66.7%
National 28.8%
International 4.5%
## Participating UK groups happy to be named in this report
(names as described by the groups themselves)

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>25% ME Group</td>
<td>support for severe ME sufferers</td>
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<tr>
<td>Action Against Allergy</td>
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<tr>
<td>Action for Sick Children (Scotland)</td>
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<tr>
<td>Action on Medical Negligence Association</td>
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<td>ADD-Lib</td>
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<tr>
<td>African and Caribbean Mental Health Services</td>
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<tr>
<td>Age Concern, Brighton, Hove and Portslade</td>
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<tr>
<td>Age UK, Cheshire</td>
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<td>Alexandra Hospital Cardiac Rehab Team</td>
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<td>Angus Cardiac Group</td>
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<td>Arthritis Care</td>
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<tr>
<td>Arthritis Care, Watford Branch</td>
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<tr>
<td>Aurora Health Foundation</td>
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<td>Barnet Heartlinks</td>
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<td>West Berkshire Neurological Alliance</td>
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<td>Working to Recovery</td>
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<td>York Carers Forum</td>
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<tr>
<td>Young Arthritis Support (I.o.W.)</td>
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<td>YoungMinds</td>
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</table>

Why do UK patients not seek help from doctors when they should?
### Why patients do not seek help from their doctors when they should (UK)

#### 76 reasons (unclassified) — number of mentions, % of total and rank

<table>
<thead>
<tr>
<th>Reason</th>
<th>Rank</th>
<th>Number</th>
<th>% of Total</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>The doctor lacks clinical knowledge of the patient’s condition</td>
<td>1st</td>
<td>77</td>
<td>24.37</td>
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<tr>
<td>The patient only receives a short consultation</td>
<td>2nd</td>
<td>27</td>
<td>8.54</td>
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<tr>
<td>The patient fears the medical consequences of a diagnosis</td>
<td>3rd</td>
<td>24</td>
<td>7.59</td>
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</tr>
<tr>
<td>The patient is aware of having a medical condition—but lacks the knowledge needed to proceed further</td>
<td>4th</td>
<td>22</td>
<td>6.96</td>
<td></td>
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<tr>
<td>The patient fears not being listened to by the doctor</td>
<td>5th</td>
<td>20</td>
<td>6.33</td>
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<tr>
<td>Difficulty in scheduling an appointment acts as a barrier to the patient</td>
<td>6th</td>
<td>19</td>
<td>6.01</td>
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<tr>
<td>The patient does not want to bother the doctor</td>
<td>7th</td>
<td>12</td>
<td>3.80</td>
<td>5th</td>
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<tr>
<td>A category of patients who may not take care of their own health: carers</td>
<td>7th</td>
<td>12</td>
<td>3.80</td>
<td>6th</td>
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<tr>
<td>The patient has a condition that is not medically recognised or accepted</td>
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<td>10</td>
<td>3.16</td>
<td>7th</td>
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<tr>
<td>The patient feels overawed by the doctor, who can be patronising or patriarchal</td>
<td>9th</td>
<td>10</td>
<td>3.16</td>
<td>7th</td>
</tr>
<tr>
<td>The patient is aware of having a medical condition—but does not see any point in seeking diagnosis/treatment</td>
<td>9th</td>
<td>10</td>
<td>3.16</td>
<td>7th</td>
</tr>
<tr>
<td>The doctor lacks communication skills</td>
<td>11th</td>
<td>9</td>
<td>2.85</td>
<td>5th</td>
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<tr>
<td>The patient fears stigmatisation, prejudice and discrimination</td>
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<td>8</td>
<td>2.53</td>
<td>5th</td>
</tr>
<tr>
<td>Waiting times for an appointment with the doctor are too long</td>
<td>13th</td>
<td>8</td>
<td>2.53</td>
<td></td>
</tr>
<tr>
<td>The patient is in a state of denial about their condition</td>
<td>13th</td>
<td>8</td>
<td>2.53</td>
<td></td>
</tr>
<tr>
<td>Language and cultural barriers inhibit the patient from going to the doctor</td>
<td>13th</td>
<td>8</td>
<td>2.53</td>
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</tr>
<tr>
<td>Getting a diagnosis or the correct balance of treatment takes too long</td>
<td>13th</td>
<td>8</td>
<td>2.53</td>
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<tr>
<td>The patient’s own health problems may make visiting the doctor difficult</td>
<td>13th</td>
<td>8</td>
<td>2.53</td>
<td></td>
</tr>
<tr>
<td>The patient fears not being taken seriously by the doctor</td>
<td>19th</td>
<td>7</td>
<td>2.22</td>
<td>5th</td>
</tr>
<tr>
<td>The patient fears being judged by the doctor</td>
<td>19th</td>
<td>7</td>
<td>2.22</td>
<td>5th</td>
</tr>
<tr>
<td>Men are particularly reluctant to visit the doctor</td>
<td>19th</td>
<td>7</td>
<td>2.22</td>
<td>5th</td>
</tr>
<tr>
<td>The patient fears that the doctor will be dismissive or unsympathetic</td>
<td>19th</td>
<td>7</td>
<td>2.22</td>
<td>5th</td>
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<tr>
<td>Gaining entry into healthcare infrastructure is difficult for people with a disability</td>
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<td>7</td>
<td>2.22</td>
<td>5th</td>
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<tr>
<td>The patient is ashamed or embarrassed at having the condition</td>
<td>24th</td>
<td>6</td>
<td>1.90</td>
<td>5th</td>
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<tr>
<td>The patient fears discrimination from within the healthcare system</td>
<td>24th</td>
<td>6</td>
<td>1.90</td>
<td>5th</td>
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<tr>
<td>The patient has had a bad experience with the healthcare system before</td>
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<td>1.90</td>
<td>5th</td>
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<tr>
<td>The patient does not want to waste the doctor’s time</td>
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<tr>
<td>The patient is not permitted to see the same doctor</td>
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<td>1.90</td>
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<tr>
<td>The patient is unable to get an appointment time that suits their lifestyle</td>
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<tr>
<td>Carers have a particular problem in finding the time to see the doctor</td>
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<td>The patient is afraid to admit failings in compliance</td>
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<td>1.58</td>
<td>5th</td>
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<td>The patient’s transport problems may make visiting the doctor difficult</td>
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<td>5</td>
<td>1.58</td>
<td>5th</td>
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<tr>
<td>The GP acts as a barrier to the specialist</td>
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<td>5</td>
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<td>5th</td>
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<tr>
<td>The patient fears not being believed by the doctor</td>
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<td>5</td>
<td>1.58</td>
<td>5th</td>
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<tr>
<td>Diagnosis and treatment may lead to unpleasant social consequences for the patient</td>
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<td>5</td>
<td>1.58</td>
<td>5th</td>
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<tr>
<td>Access to specialists: other comments</td>
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<td>5</td>
<td>1.58</td>
<td>5th</td>
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</tbody>
</table>
### Why patients do not seek help from their doctors when they should (UK)

#### 76 reasons (unclassified) — number of mentions, % of total and rank

<table>
<thead>
<tr>
<th>Reason</th>
<th>Rank</th>
<th>No.</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>The patient lacks the confidence to go (or relate) to the doctor</td>
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<td>The patient fears being reprimanded by the doctor</td>
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<td>4</td>
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<td>The doctor does not prescribe the treatment that the patient wishes</td>
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<td>4</td>
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<tr>
<td>The patient fears a lack of confidentiality</td>
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<td>The patient fears being seen by the doctor as a nuisance, or as neurotic</td>
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<td>The physical mechanisms involved in booking an appointment may make visiting the doctor difficult</td>
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<td>1.27</td>
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<td>The healthcare system lacks resources</td>
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<td>The patient is not aware of having a medical condition</td>
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<td>The patient fears that the doctor will be arrogant and intimidating</td>
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<td>People do not like to go to the doctor</td>
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<td>Waiting times for an appointment with the GP are too long</td>
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<td>3</td>
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<td>The patient’s carers may lack understanding or communicational skills</td>
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<td>3</td>
<td>0.95</td>
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<td>The patient fears being denied informed consent</td>
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<td>The patient lacks the time to visit the doctor</td>
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<td>Patients in rural areas find travel to the doctor particularly difficult</td>
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<td>The patient fears the doctor’s reaction</td>
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<td>The patient fears that the doctor is not interested in them</td>
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<td>The patient fears the legal consequences of diagnosis</td>
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<td>Family considerations may inhibit the patient from going to the doctor</td>
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<td>Different doctors give conflicting advice</td>
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<tr>
<td>The doctor does not meet the patient’s needs</td>
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<td>The patient fears that the doctor is motivated only by financial considerations</td>
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<tr>
<td>Being honest with the doctor is impossible—whatever the reason</td>
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<tr>
<td>Lack of specialists</td>
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<tr>
<td>The doctor’s distance from the patient may make visiting the doctor difficult</td>
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<td>Lack of both primary-care doctors and specialists</td>
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<td>0.32</td>
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<td>The patient fears the side effects of medication</td>
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<td>The cost of travel to the doctor may make visiting the doctor difficult</td>
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<tr>
<td>Lack of primary-care doctors</td>
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<td>0.32</td>
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<tr>
<td>The patient fears discrimination from society at large</td>
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<td>0.32</td>
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<tr>
<td>The patient has a poor relationship with the doctor</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
<tr>
<td>The patient fears being made to feel stupid by the doctor</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
<tr>
<td>The patient fears having to take time off work or becoming unemployed</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
<tr>
<td>The patient fears poor staff attitudes in general</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
<tr>
<td>The patient may not take care of their own health</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
<tr>
<td>The facility’s secretarial/booking staff act as a barrier to the patient</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
<tr>
<td>The doctor is not willing to see a younger patient</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
<tr>
<td>The patient fears drug interactions</td>
<td>= 61st</td>
<td>1</td>
<td>0.32</td>
</tr>
</tbody>
</table>
Country profile:

% of patient groups in the global arm of the study

<table>
<thead>
<tr>
<th>Country</th>
<th>% of Patient Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Armenia</td>
<td>0.1%</td>
</tr>
<tr>
<td>Australia</td>
<td>6.2%</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>0.1%</td>
</tr>
<tr>
<td>Belgium</td>
<td>0.6%</td>
</tr>
<tr>
<td>Bermuda</td>
<td>0.1%</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>0.2%</td>
</tr>
<tr>
<td>Brazil</td>
<td>0.5%</td>
</tr>
<tr>
<td>Canada</td>
<td>9.5%</td>
</tr>
<tr>
<td>Cuba</td>
<td>0.1%</td>
</tr>
<tr>
<td>Cyprus</td>
<td>0.2%</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>0.8%</td>
</tr>
<tr>
<td>Denmark</td>
<td>1.0%</td>
</tr>
<tr>
<td>Estonia</td>
<td>0.3%</td>
</tr>
<tr>
<td>Finland</td>
<td>0.7%</td>
</tr>
<tr>
<td>France</td>
<td>0.7%</td>
</tr>
<tr>
<td>Hong Kong</td>
<td>0.1%</td>
</tr>
<tr>
<td>Hungary</td>
<td>0.1%</td>
</tr>
<tr>
<td>Ireland</td>
<td>3.5%</td>
</tr>
<tr>
<td>Italy</td>
<td>0.1%</td>
</tr>
<tr>
<td>Jamaica</td>
<td>0.1%</td>
</tr>
<tr>
<td>Kenya</td>
<td>0.1%</td>
</tr>
<tr>
<td>Latvia</td>
<td>0.3%</td>
</tr>
<tr>
<td>Lithuania</td>
<td>0.3%</td>
</tr>
<tr>
<td>Malawi – Republic of Malawi</td>
<td>0.1%</td>
</tr>
<tr>
<td>Malaysia</td>
<td>0.1%</td>
</tr>
<tr>
<td>Malta</td>
<td>0.6%</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2.5%</td>
</tr>
<tr>
<td>New Zealand</td>
<td>6.2%</td>
</tr>
<tr>
<td>Norway</td>
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</tr>
<tr>
<td>Pakistan</td>
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</tr>
<tr>
<td>Philippines</td>
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</tr>
<tr>
<td>Poland</td>
<td>1.7%</td>
</tr>
<tr>
<td>Portugal</td>
<td>0.3%</td>
</tr>
<tr>
<td>Romania</td>
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</tr>
<tr>
<td>Russia</td>
<td>0.1%</td>
</tr>
<tr>
<td>Rwanda</td>
<td>0.0%</td>
</tr>
<tr>
<td>Slovakia</td>
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<tr>
<td>Slovenia</td>
<td>0.6%</td>
</tr>
<tr>
<td>South Africa</td>
<td>0.7%</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>0.1%</td>
</tr>
<tr>
<td>Sweden</td>
<td>3.8%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>0.1%</td>
</tr>
<tr>
<td>Turkey</td>
<td>0.1%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td></td>
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<tr>
<td>United States</td>
<td>17.1%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>36.5%</td>
</tr>
<tr>
<td>Uruguay</td>
<td>0.1%</td>
</tr>
<tr>
<td>Uzbekistan</td>
<td>0.2%</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>0.1%</td>
</tr>
</tbody>
</table>
November 2011

Appendix 2: Company rankings

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