

ATTITUDES TOWARDS CONSENT AND DECISION MAKING

Prepared for the General Medical Council by Ipsos MORI
September 2018



EXECUTIVE SUMMARY

Research was conducted by Ipsos MORI on behalf of the General Medical Council (GMC) to explore the principles in the GMC's *Consent* guidance, last published in 2008. The guidance details the principles for good practice in making decisions, covering areas such as working in partnership, sharing information and discussing treatment options, discussing side effects, making decisions and capacity issues. This research fed into a review of the guidance with the aim of updating it.

Methodology

The research was conducted with 100 people in 2018, across England, Wales, Scotland and Northern Ireland. Participants took part in face-to-face in depth interviews and face-to-face and online group discussions. The sample included people from nine audiences who were of particular interest to the GMC and who had characteristics that meant they would be unlikely to have taken part in the wider consultation.

The numbers in each group were very small, so the findings should be taken as insights and perspectives,

rather than definitive. Nevertheless, clear themes emerged across the different groups, with commonality in participants' concerns and views.

Roles in decision making and consent

- People generally feel that the role of doctors is to engage in discussions with patients and offer their view on the best way forward.
- While people feel it is appropriate for doctors to try to engage patients in discussions, there is acknowledgement that some patients may be less capable of being involved. In such cases, for example where patients lack capacity, there is a tendency to believe that doctors should consult with those close to the patient, to help them arrive at the best possible decisions.
- There are also some patients who prefer *not* to be involved in discussions and would rather leave this to doctors. These attitudes are more prevalent in people with certain characteristics or with particular circumstances, such as those with mental health

conditions or those living in care homes.

- People identify a number of benefits to doctors involving carers, relatives and others who are close to patients in discussions about their treatment or care. These include helping the patient give and receive information (i.e. by simplifying language); being involved in decisions where the patient is unable to be; providing additional information about the patient; as well as providing emotional and practical support to the patient.
- However, they also note that doctors should exercise caution in this regard and be aware of potential drawbacks. This includes the risk of relatives being too emotionally involved to make sound judgements.
- People are, on balance, in favour of the idea of doctors involving other members of the healthcare team in discussions about decisions.

EXECUTIVE SUMMARY

Communication and supporting decision making

- Patients take others with them to appointments or consultations with doctors for moral support, to help them remember information and to assist them in their understanding.
- Since people bring other people with them for these different reasons, it is useful for doctors to understand exactly what the person's role is. This will help doctors determine the extent to which they should involve them and the most appropriate way of doing so.
- In terms of information provision, people tend to be positive towards receiving information in a range of formats, such as graphs and models. They also respond well to the use of real life examples and statistics.
- Patients are keen for doctors to use terminology that they can easily understand, avoiding medical jargon which can be alienating and intimidating.

- The demeanour of a doctor is important, with patients appreciating doctors who demonstrate active listening and appear to be friendly.

Supporting patient decision making

- Patients are positive about being provided with choice by doctors and the reasons for this include feeling that doctors are being open and transparent, empowering patients and allowing them to make informed decisions.
- However, there can be downsides to being given choice, including the risk of patients feeling as though they do not have sufficient knowledge to make decisions and also their fear of making a choice that they later regret.
- In general, people would like doctors to provide them with a small number of the most suitable options, to reduce the risk of overwhelming them. They would also prefer for doctors to provide a steer about what

they believe is the best option for them.

- Some patients report that doctors usually outline the risks and benefits of treatments with them, while others say doctors tend not to. Patients are generally keen for doctors to try to run through the possible risks and benefits, particularly those concerning side effects, in all appointments or consultations.
- People report that they can feel under time pressure to make decisions when they visit GPs, but this is less common when in appointments or consultations with other types of doctors – particularly those in hospital settings.

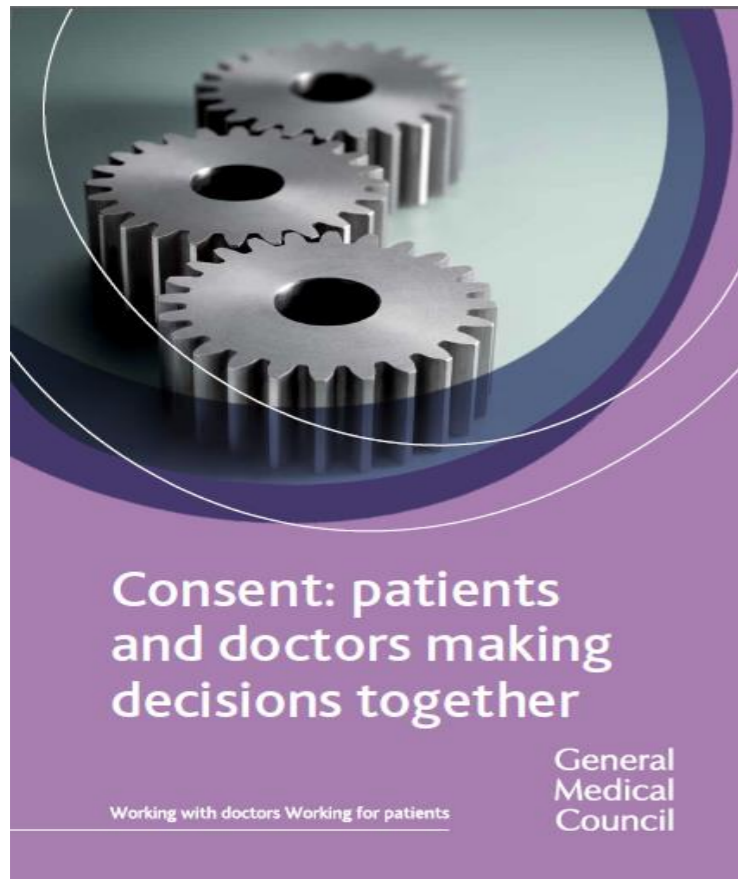
EXECUTIVE SUMMARY

Partnership in decision making

- People tend to want to be very involved in decisions that concern them and that involve their healthcare. However, they also value the expertise of doctors and rely on them for a clear steer.
- This said, some people do not always feel sufficiently involved in the decision making process. They attribute this to such factors as a lack of time, inadequate information provision and feeling that doctors are not always listening to them.
- There are patients who do not feel comfortable with raising issues or concerns. They feel doctors could assist them by providing a friendly, welcoming interaction where they display active listening.
- People mention other ways doctors could help them to be included, for example by providing information in different formats and, for certain patients, involving interpreters and translators.



BACKGROUND



The GMC **regulates doctors in the UK** and has a purpose to protect, promote and maintain the health and safety of the public by **ensuring proper standards of medical practice**. To achieve this, it has the power to give advice to doctors on standards of professional conduct, performance and medical ethics.

The GMC's **Consent guidance was published in 2008**. It lays out the principles for good practice in making decisions, covering areas such as working in partnership, sharing information and discussing treatment options, discussing side effects, making decisions and capacity issues.

To ensure the guidance to doctors remains **clear and relevant to doctors, complies with the law and reflects what is important to patients**, it is important that the GMC regularly reviews it. To this end, the GMC is

currently reviewing the Consent guidance with view to updating it.

Alongside a wider consultation on the revised guidance and research carried out with doctors*, the GMC commissioned Ipsos MORI to **explore patient and public attitudes towards consent and decision making**, with a focus on a number of **seldom-heard groups**.



Ipsos MORI

*'Doctors' attitudes to consent and shared decision making': <https://www.gmc-uk.org/about/what-we-do-and-why/data-and-research/research-and-insight-archive/doctors-attitudes-to-consent-and-shared-decision-making>.

RESEARCH

AIMS

The aim of the research was to **test policy positions in the draft *Consent* guidance**, exploring patient and public attitudes to the key issues.

The research aimed to engage specifically with groups of individuals who are **unlikely to participate in a public consultation, either in contributing by writing or by attending consultative events**. Such individuals are also more likely to experience **barriers to accessing healthcare**, be less able to provide voluntary and informed consent, or make a decision.



METHODOLOGY

We engaged with **100** people between **19th March 2018** and **16th July 2018**.

Participants were **recruited through a mixture of channels**, including on-street face-to-face recruitment, asking participants to put the recruiter in touch with others they know who fit the recruitment criteria, and via representatives at a number of organisations that support and provide information to certain groups.

We used a **mixed methods approach** to the research, involving face-to-face interviews, telephone interviews, face-to-face and online discussion groups. The research method was chosen with the **audience of interest in mind**. For example, whether or not the issues discussed could be particularly sensitive for a specific group.

We spoke with people from **nine different seldom-heard groups**. However, some people in the study have characteristics common to more than one group (e.g. some participants with limited English are also refugees).

Please see the table on the following page for a break down of the different participant groups.

We also conducted **four telephone interviews with stakeholders from representative organisations** to explore their views – from their professional perspective – on consent and decision-making with regard to seldom-heard groups. Each of the stakeholders broadly matched up with one of the seldom-heard groups included in the research. We spoke with individuals from Alzheimer's Society (a research charity for people living with dementia and their carers), Citizens Advice (an organisation that provides advice to the public and strives to change policy through research), Each One Homes (an organisation which provides support to young people), and Sign Health (a charity that works towards improving the health and wellbeing of people who are deaf).

The discussions with participants were **focused around the key themes in the draft Consent guidance** to gain insight on the participants' views about consent and decision making in health care.

Fictional scenarios were also used to stimulate discussion, designed to further explore the core principles in the draft Consent guidance, such as involvement in decision making.

The scenarios were chosen **to explore issues that are likely to be pertinent to certain groups**. For example, a scenario involving an elderly person deciding whether or not to have the flu jab was used in the group with relatives of people living in care homes.



METHODOLOGY

Group number	Group name	Methodology	Number of people engaged	Country
1	People living in care homes	1 group	7	England
		1 depth interview		Northern Ireland
2	Relatives of people living in care homes	2 mini groups	8	Wales
3	Carers	8 depth interviews	12	England
		4 tele-depth interviews		Northern Ireland
4	People who have experienced detention by the state and people who have undergone compulsory assessment/treatment	8 depth interviews	8	Scotland
5	People with limited English	8 depth interviews	8	England
6	People with communication needs	8 depth interviews	8	England
7	People with health conditions that may affect their mental capacity	3 depth interviews	10	England
		4 depth interviews		Northern Ireland
		3 depth interviews		Scotland
8a	Asylum seekers and refugees	6 depth interviews	6	England
8b	People from the gypsy and traveller community	2 mini groups	8	England
8c	People from cultures with different attitudes towards consent (e.g. Muslim women and individuals who consult their religious leaders when making decisions about their healthcare)	6 depth interviews	6	England
9	Young adults	2 online groups	15	England
	Stakeholders	4 tele-depth interviews	4	England

PRESENTATION AND INTERPRETATION OF THE FINDINGS

Qualitative research is used to explore **why people hold particular views**, rather than to estimate or quantify how many people hold those views.

Such research is **illustrative**, rather than statistically representative, of a wider population.

When interpreting the findings from this research, it should be remembered that the **results are based on a small number of people** who have discussed the relevant issues in depth; the views stated here are **not facts** – rather they are the **participants' perceptions**.



STRUCTURE OF THE REPORT

The report is structured around the GMC's consultation questions, which asked people belonging to seldom-heard groups for **feedback on the draft guidance**.

The report presents findings around **four main themes**, which **mirror the structure of the wider consultation**:

1. Roles in decision making and consent.
2. Communication and supporting decision making.
3. Supporting patient decision making.
4. Partnership in decision making.

The data from group discussions and depth interviews were thematically analysed and the report presents the findings across all groups.

Where there are any differences in opinion by group, these are presented in a light grey box, along with a description of the group.

The report also includes several case studies, which describe the real-life experiences of individual participants, based on the interviews conducted. Their names have been changed to protect their identities. These case studies are presented in pink boxes throughout the report, along with a description of the individual, they relate to.



1. ROLES IN DECISION MAKING AND CONSENT

CHAPTER SUMMARY

The role of the doctor is generally seen to be to **guide patients** towards the decision that they feel is in the patient's best interests.

People tend to feel that doctors should always attempt to **involve patients**, by explaining their thinking and providing information clearly.

Opening up the discussion helps patients to **arrive at informed decisions** that align with what doctors consider to be in their best interests.

There are variations in opinion about whether it should be the doctor or the patient who has the **final decision**.

People acknowledged that some patients may be **less able to be involved** however, such as those **lacking capacity**:

- In such cases, people tend to agree that doctors should consult with others who are close to the patient, before arriving at decisions.

People with health conditions affecting their mental capacity talk about being **glad that doctors have made decisions** on their behalf at times.

Some groups of people in this study have a greater propensity to say that they **do not want to be involved in decisions** about their care:

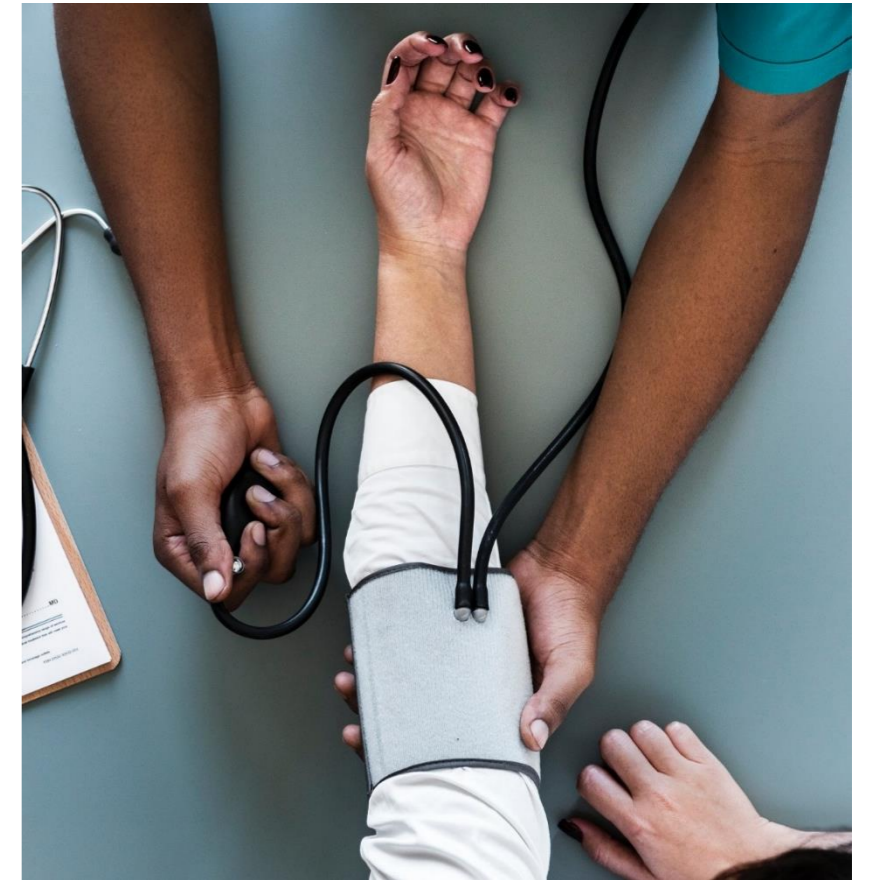
- Those with mental health conditions, those living in care homes and those from the gypsy and traveller community.

People are **positive** to patients having the **option to involve carers, relatives or others** who are close to them in decisions:

- However, there are some **considerations and concerns**, including the risk that they may be too emotionally involved to help.

Patients tend to be **positive** to the idea of doctors **involving other members of the healthcare team**:

- This provides a safeguard, extra expertise and could reduce the workload of doctors.



THE ROLE OF THE DOCTOR OVERALL

Participants were asked what they consider to be the role of any type of doctor, such as a GP, a doctor in an outpatient clinic or a doctor that they might see if they were having surgery in hospital.

People generally see the doctor's role to be to provide the patient with information and to **guide them** towards the decision that they consider to be most appropriate for the patient.

The amount of steer patients want **depends on the nature and severity** of their health conditions. Generally, patients are more comfortable with making smaller decisions. For **serious** health conditions (such as cancer, or when a patient is at risk of harming themselves or others), and **life-threatening** health conditions, there is a preference for doctors deciding.

The doctor is seen as best placed to make decisions, given their **medical knowledge, expertise and understanding** of what is safest. It is the doctor's role to act in the patient's **best interests**.

However, there is acknowledgement that these decisions affect the patient and their body and so it is best for doctors to **involve patients**, where practical. Patients would generally like doctors to talk scenarios through with them and to explain their rationale.

Participants from gypsy and traveller communities

- Had a particularly strong tendency to say that they would like doctors to guide them.
- Not all of those included in the research could read and write and some expressed the view of feeling that doctors occupied a position of authority. This potentially helps to explain why they were particularly likely to desire guidance from doctors.

The doctor should guide me to make a decision because that's his field...and I am sick. I have no knowledge in the area, so he should be able to provide me with all the help I need to make a decision."

(Person with limited English)

As long as I felt my opinion was being considered properly, I'm happy to leave most involvement to the doctor."

(Young adult)

If it was something complicated, like if I had cancer...I would think that you would want to put it into the hands of others."

(Person living in a care home)

THE ROLE OF THE DOCTOR IN DIFFERENT SITUATIONS

Involving the patient

People tend to want the doctor to involve the patient by **providing clarity about their thinking, explaining information clearly** and opening up a **discussion** with the patient.

This helps patients arrive at sensible, **informed decisions** that align with what the doctor considers to be in their **best interests**.

However, there is acknowledgement that **some patients may be less able** to be involved, such as those who lack capacity.

 ***The doctor has to respect the patient's decisions but should always advise what they believe is best for the patient's wellbeing.***
(Young person)

The final decision

There are **variations in opinion** about **whether the final decision should be the doctor's or the patient's**.

Some people believe it is **ultimately up to patients to decide**, even if this means going against a doctor's recommendation. However, others **feel doctors need to persuade patients to take their advice** to ensure that patients receive the best possible care. This is because of the medical knowledge and experience that doctors are able to bring to the interaction.

Some feel this **depends on the seriousness of the decision** and that doctors should have the final say in life or death situations.

When patients say they do not want to be involved in decisions

People have mixed views about what doctors should do

when a patient does not want to be involved in making decisions about their healthcare or treatment. The range of suggestions include:

- Doctors **must encourage** them to get involved and gain their input.
- Doctors should **engage the patient's family or others close to them**.
- Patients should **sign a waiver** to indicate that they do not want to be involved. As suggested by a carer, they 'choose not to choose'.
- Doctors should be **able to make decisions on behalf of their patients** in these circumstances

There is acknowledgement that the way doctors should proceed in such circumstances depends on **how close their relationship is** with the patient and whether the patient is in **pain**.

THE ROLE OF THE DOCTOR, THE PATIENT AND OTHERS WHEN PATIENTS LACK CAPACITY

In cases where a patient lacks capacity

Participants were asked to think about a situation in which the patient lacked the mental capacity to decide. This situation was defined as being where at the time, the patient was unable to make a decision because of an impairment of, or a disturbance in, the functioning of their mind or brain.

People generally say that doctors should **consult with other people** who are **close to the patient**, such as the next of kin, relatives or support workers before making decisions on their behalf.


In situations where a patient does not have such contacts, people tend to consider it to be appropriate for doctors to **make decisions on a patient's behalf**.

Doctors could also discuss the case with other doctors, or research other similar cases, before proceeding.

People with health conditions impacting on their capacity

Discuss occasions where they have been glad that doctors made decisions for them. For example:

- A patient living with Parkinson's disease said he prefers to be removed from decision making because he is not interested.
- Another patient, who experienced suicidal ideation, prefers the doctor to take the lead because she feels under a lot of pressure when she has to make decisions.

 ***When the doctor is aware of how bad my state of mind is, then they should take care of making decisions."***

(Person with a health condition affecting their mental capacity)

Relatives of people living in care homes

Offer differing views about the level of involvement that people in care homes should have in discussions about their treatment and care.

There is some feeling among those with Lasting Power of Attorney (LPA), for the health and personal welfare of those living in care homes that it is better for the person in the home *not* to be involved. This is because they feel they are unable to make a useful contribution to the discussion with a doctor.

THE ROLE OF THE PATIENT

People were asked how much involvement they generally want to have in decisions about their treatment or care.

Patients generally agree that it is best for doctors to involve them in decision making.

However, some patients express **a preference for less involvement** and would rather leave decision making to doctors.

There is a greater propensity for this among those with **mental health conditions**, those **living in care homes** and people from the **gypsy and traveller community**.

Case study – living with a mental health condition

Claire suffered with postnatal depression and anxiety. During this time, she described experiencing “brain fog” and because of this, she preferred doctors to guide her regarding the best course of action.

 ***Whatever they [doctors] tell you, you've got to do anyway.***

(Person from the gypsy and traveller community)

Case study – caring for a person with a mental health condition


Jill is an informal carer for her son, who has a mental health condition. She feels that there are times when a GP's knowledge and experience must override anything else. She stated that sometimes, it is necessary for a doctor to say “No sorry, I've seen what happens next [in a similar case involving mental health]. I've seen an episode of this – this is following a pattern”. Jill believes that doctors should take charge where they feel it is in a patient's best interests.

THE ROLE OF CARERS AND RELATIVES

Participants were asked how helpful they thought it would be to involve their friends, carers, relatives and others they are close to in decisions about their care or treatment.


Overall, people tend to **be positive to patients having the option to involve carers, relatives or others** who are close to them in decisions about their treatment and care.

Carers are particularly positive about the contribution they can make.

 ***The clinician is reliant on truthful, heartfelt info coming from a carer or relative.***
(Informal carer)

Contribution of carers/relatives	Benefits
Helps patients to give, receive and understand information	<ul style="list-style-type: none"> • They can simplify language to help the patient understand
Involvement in decision making	<ul style="list-style-type: none"> • Necessary where the patient lacks capacity
Provides extra information about the patient	<ul style="list-style-type: none"> • They can pick up on issues the patient is unaware of • They can discuss medication • They relay information to the patient lacks capacity
Provides emotional support and reassurance	<ul style="list-style-type: none"> • They can help to keep the patient calm. • They can give encouragement
Conveys a patient's wishes	<ul style="list-style-type: none"> • Necessary where the patient lacks capacity
Provides practical support to patients	<ul style="list-style-type: none"> • E.g. to ensure the patient attends appointments

 ***My doctor said it was best to involve others so I knew I have that extra support.***
(Young adult)

 ***It's important because it gives them support and strength. If you are carrying a table, a load on your own is going to be really heavy. If you have someone supporting you, it will be lighter, so it is really important.***
(Bengali man)

THE ROLE OF CARERS, RELATIVES AND OTHERS

Some people feel there are extra reasons to involve relatives and carers.

They are affected by decisions: These may affect them directly and they are the ones who will be looking after the patient.

Doctors could deliver news to them first: This would allow the family to tell the patient in their own way and reduce the patient's distress.

Doctors can ask them to **persuade the patient to take their advice.**

There were other comments made in relation to involving friends, representatives from charitable organisations and prison staff.

Friends


Some comments from asylum seekers and refugees indicate that they do not find it beneficial to involve too many people, besides the patient's family. There is a perceived risk of gossip and stigmatisation for the patient.

Charitable organisations

Some mention that these could play a role in helping vulnerable people.

Prison staff

One individual, who had been detained by the state, mentioned that he feels involving prison staff in conversations about medical decisions is acceptable.

 *Say if I had some really bad complaint and I said, 'Well, I'm not having that treatment' I'd like the doctor to look up to my [spouse] and say 'Look, she needs it. Can you try and get her to have it?'"*
(Person from the gypsy and traveller community)

CONSIDERATIONS AND CONCERNS ABOUT INVOLVING CARERS AND RELATIVES

People expressed caution about involving carers


Some people were concerned about involving carers and this viewpoint was more prevalent among people who were not themselves carers. They noted that:


- Doctors need to be confident that carers are **trustworthy**.
- The appropriateness of involving carers depends on which **type of carer** they are. For example, some carers will be much closer to the person they care for than others.

Points for doctors to be mindful of

People raised considerations for doctors to be aware of when:

- Family may be **too emotionally involved** to make sound decisions.
- Relatives **lack medical knowledge**.
- Patients may be pressured by relatives.
- Doctors should provide patients with the **opportunity to speak to them alone**, without the carer or relative being there.
- There is a particular issue in **cultures where men tend to make decisions for women** and there is a risk that women will be **pressured** or their views will **not be taken into account**.
- Some young people feel that the involvement of others could **complicate things** and negatively impact on the patient's decision making.

 *It can make things or decisions more complicated and confusing and [Others] might influence your final decision."*
(Young adult)

 *Wouldn't want a hyperventilating family to be involved."*
(Muslim woman)

THE ROLE OF OTHERS IN THE HEALTHCARE TEAM

People are generally positive to the idea of doctors involving other members of the healthcare team in decisions about their treatment or care. There were a number of reported reasons for this.

Acts as a positive safeguard

- Decisions do not all rest with one person - second opinion is valued.
- In a multi-disciplinary team, different healthcare professionals spot different things.
- Helpful extra opinion when the doctor and patient disagree.

Others may have greater expertise and skills

- For example, awareness of alternative treatments.
- May be better at conveying information.
- Reduces the doctors' workload (this was a point of particular relevance to GPs).

Means that the doctor can spend more time with patients

- Comforting patients.
- Helpful for people without others to turn to.

Examples of who could be involved	Possible negative aspects reported
<ul style="list-style-type: none">• Other GPs.• Personal Officers in prisons.• Drug workers.• Pharmacists.• Nurses.• Health visitors.• Healthcare assistants.	<ul style="list-style-type: none">• Patients may feel scared by too many people being involved.• Poor communication between teams.



It stops mistakes happening when it's all down to one person. I think sharing information is key."

(Professional carer)



More heads are better than one!"

(Bengali man)

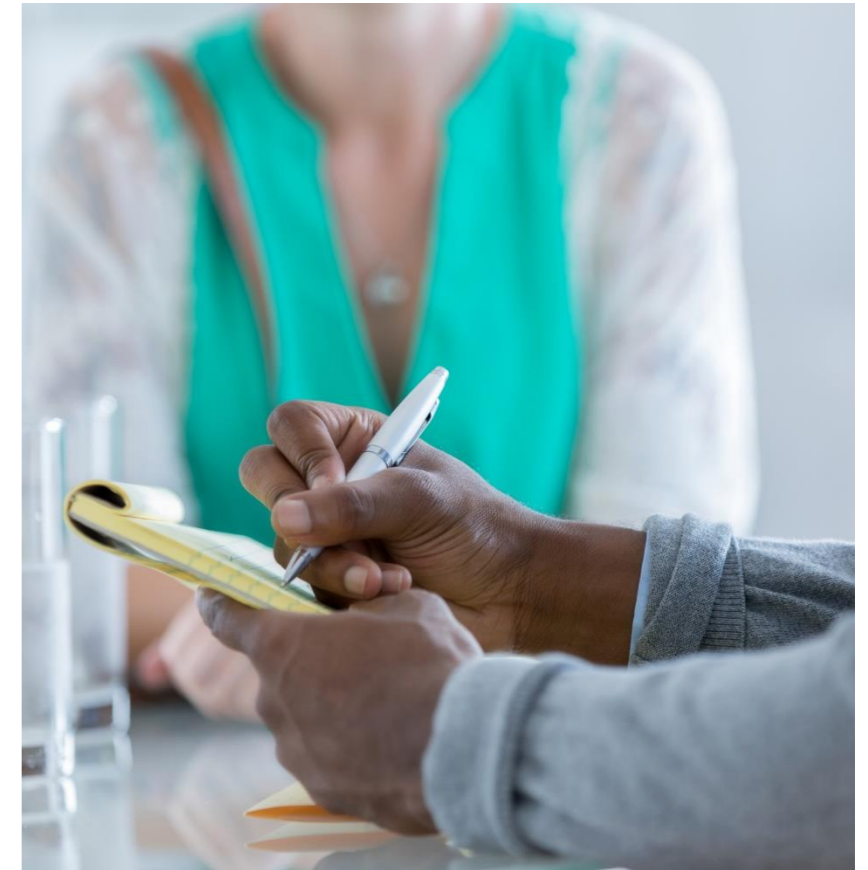


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2. COMMUNICATION AND SUPPORTING DECISION MAKING

CHAPTER SUMMARY

- Those who **take others with them** when visiting the doctor do so to **provide emotional support, help remember information** and to **assist them with interpretation** and understanding.
- Participants feel that **doctors should verify the role of the person accompanying the patient**, with the patient if possible, which would make for a more successful appointment.
- Participants reported an appreciation for information provision in **non-verbal**, but **engaging or accessible formats such as visual aids, graphs, or models** of the human anatomy.
- **Written information, and signposting to online sources, can be useful** for those who struggle with communication, and also where doctor's are pushed for time.
- When **doctors speak too quickly or use medical jargon, patients can be alienated.**
- There is a **general lack of awareness around the availability of interpreters** in healthcare, which would benefit those who struggle with language barriers.
- When doctors come across as **friendly and caring** and **demonstrate active listening**, this makes patients feel involved, reassured and not intimidated.
- Although some already do prepare in advance of seeing a doctor, there is a general sense that **a document about how to prepare for an appointment/consultation would be helpful.**
- Participants **appreciate the use of real-life examples and statistics** to aid their understanding and for reassurance.
- Some voiced a **desire for a record** (written, and even audio) **of consultations.**



VISITING DOCTORS

ALONE OR ACCOMPANIED BY OTHERS

Participants were asked whether they ever take somebody with them when they go to see a doctor and if so, what their reasons were.

Participants who take others along with them to their consultations or appointments reported doing so **for the moral or emotional support**. Especially where patients are anxious about engagement with medical professionals, e.g. Women from the gypsy and traveller community.

For others, taking someone along with them was more about **assisting them to remember and retain information**, especially those with mental health problems or limited English.

Those who **go by themselves either do so because they want the privacy**, or because of the lack of availability of someone to go with them.



Helpful to go with someone else, so they can take in any info. you miss."

(Young person)

When a patient is accompanied by someone else to an appointment or consultation

- They can feel **more listened to** – for example a participant who had been detained by the state talked about taking his mother as he felt it would encourage the doctor to listen.
- The **person accompanying them can act as an interpreter**, in the absence of a professional. However, patients note that this is not ideal because sometimes they do not want to disclose personal information in front of them.
- They can also **help patients with communication problems to understand the information** being conveyed to them by the doctor.
- However, doctors should be encouraged to establish the **level of involvement** of the person accompanying the patient. For example, whether the patient would like them to be involved in the conversation and if so, to what extent. Ideally, doctors would discuss this with the patient.

Carers

- Reported helping to present a patient's case
- Reported helping to explain things to the person they care for.
- Took notes on behalf of the patient.
- Those with Lasting Power of Attorney (LPA) for health and personal welfare attended consultations to absorb information on the patient's behalf.




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THE PROVISION OF INFORMATION

Participants were asked whether doctors ever use visual aids such as diagrams or pictures and if so, what their views were about these.

When doctors use **visual aids** it helps patients to understand better. A number of these aids were positively welcomed by participants:

- **Drawings** to explain medical situation.
- **Images** on computer screens.
- **Visual test results**, such as x-rays.
- **Pictures**, conveying disease or surgery.
- **Graphs** to convey side effects.
- **Diagrams** to demonstrate using medical devices.
- **Models** of the human anatomy to explain affected areas.

 *I think explaining it verbally is really important but the handouts are helpful to read over and remember what has been said."*

(Young adult)

The provision of **written information** (leaflets and letters), and signposting to online resources:

- Can help patients when doctors are pushed for time.
- Is useful for people who struggle to retain information.
- Can be taken away and translated.

Participants from gypsy and traveller communities

- There are low levels of literacy within the gypsy and traveller community, hence written information is not always appropriate.
- Verbal communication is key.
- Welcome the use of visual aids to explain medical information.



I think they [doctors] presume that I can read and write. I know people outside the traveller community who can't read and write, so they should ask you really."

(Female from gypsy and traveller community)



I'd have to throw it [written information] in the bin because it's just paper to me."

(Male from gypsy and traveller community)



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LEVEL OF SATISFACTION WITH COMMUNICATION METHODS USED

Participants were asked about the interactions they have with doctors. They were questioned about what has worked well and what could be improved.

When patients are given verbal information by doctors

- Speaking at a **pace patients can understand** is paramount - particularly for people with limited English, care home residents, refugees and people with communication needs, or when the doctor has a strong accent.
- Doctors should **minimise the use of medical terminology**.
- Patients would like the **opportunity to clarify** what a doctor is telling them.
- The lack of awareness about/the availability of **professional interpreters** amplifies the difficulties with communications for people with limited English.

There were positive accounts of doctors modifying their language to aid understanding or using translation tools to help the interaction. One person explained that the doctor started with complicated information but then broke this down to make it more manageable.

Views about the volume of information

When asked about the amount of information they like to receive from doctors, participants had **varying views** on the 'right' amount. The level of information desired depended on personal preference; too much information could be hard to absorb, while too little could be insufficient.



I get discouraged sometimes to go and see [the doctor] because I know that when I get there, they won't understand me."

(Person with limited English)



They [doctor] can overload you, especially when you're changing medication."

(Person with a health condition affecting their mental capacity)



Just right. Good...The more information, the better."

(Person with limited English)

THE IMPORTANCE OF TONE AND A FRIENDLY APPROACH

People are more positive about their experiences when doctors demonstrate **active listening** and come across as **caring and friendly**. This behaviour helps patients feel:

- Involved.
- Reassured and at ease.
- Unintimidated by the doctor.

💬 *She [relative] obviously doesn't know what's being said to her, but they talk to her as if she does."*
(Relative of person living in a care home)

💬 *She [the doctor] communicates clearly and gives me a lot of encouragement, telling me everything is going to be OK... she is really nice."*
(Person with a health condition affecting their mental capacity)

💬 *He [doctor] hears me, but doesn't give consideration to what I have said."*
(Person with limited English)



PREPARING FOR A CONSULTATION

Participants were asked how, if at all, they prepared for appointments or consultations with a doctor.

Patients exhibit a range of behaviours in terms of preparing for a consultation.

Where people do prepare before they visit a doctor, they tend to do so in one, or a combination, of the following ways:

- **Looking online** – to search for symptoms, or to 'google' a disease or condition.
- **Speaking to others** – friends, family members or a pharmacist – to gather information or to seek advice.
- **Noting down questions or points to cover** – so people did not forget.

People with health conditions affecting their mental capacity, and those from non-British cultures, reported preparation before an appointment for different reasons. Their perception of **preparing beforehand** was:

- in order **to be taken more seriously by the doctor.**
- and/or **to be treated better by the doctor.**

The **general consensus** was that **a document available to help people prepare for an appointment or consultation** with a doctor **would be helpful:**

- ✓ Could reduce anxiety.
- ✓ Would help patients think about what questions to ask.
- ✓ Would help patients get the most out of consultations/appointments.
- ✓ Could reduce anxiety.
- ✓ Would help patients think about what questions to ask.
- ✓ Would help patients get the most out of consultations/appointments.

However, **there were some who thought such a document would be a waste of resource** and others who would not benefit because of literacy issues – a particular issue for the gypsy and traveller community. Such a document **would need to be available in multiple languages.**

THE USE OF REAL LIFE EXAMPLES

Participants were asked whether doctors ever used real life examples to help them understand what they are telling them. They were then asked their views about this.

The use of real life examples and statistics

- These were welcomed by most patients and seen to be reassuring.
- They were also seen to **aid understanding** by **contextualising information**.
- Patients had experienced doctors using these to **explain the benefits and drawbacks of treatments** or to explain **the likelihood of disease progression**.

However, a minority were less positive about the use of real life examples and statistics. Reporting **these might heighten concerns or cause worry** so they would rather not know.

Case study – through the eyes of an informal carer

Mary is an informal carer to her adult son, Robbie, who has autism and fluctuating capacity. Mary does not have LPA for health and personal welfare for Robbie, but cares for him full-time. Mary says that sometimes Robbie wants to go to see the doctor by himself, but Mary worries that he will not provide the doctor with the important information that is needed and so she provides him with notes. When Mary does accompany him, she finds *“my GPs talk to my son, they don't look at me in the consultation...treat him as an adult in his own right... really on the ball...”* However, there are times where Mary has felt that Robbie has been dismissed by the GP and that they have been rushed during the consultation. This is problematic for Robbie because he needs longer to articulate himself due to his autism. She has tried to explain to the receptionist that they need a longer appointment, but it is difficult to get a double-slot. Doctors sometimes draw diagrams, give leaflets out or direct Robbie to online sources of information. These are really helpful for him because he is an avid reader and when his mental health is deteriorating, visual aids are better than written or spoken information. Sometimes the doctor has contextualised the information by saying that something applies to one in five hundred people. Robbie responds positively to this and feels he was being treated as an intelligent person.















I think its very important and reassuring to know that a lot of people have been in similar situations. You know the risks involved.”

(Informal carer)



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SUGGESTIONS FOR IMPROVING COMMUNICATION

Improvement	Groups for whom this was of particular importance	Value for all patients
 Smile, use open body language and be friendly.	People with limited English. Refugees and asylum seekers.	Builds trust and rapport. Encourages people to feel they can speak freely.
 Use simple terminology and speak slowly.	People with communication needs.	Helps people to understand and absorb information.
 Be prepared to repeat information.	People with limited English. Refugees and asylum seekers.	Assists people in following information and helps to overcome language barriers.
 Provide reassurance.	Participants from gypsy and traveller communities. People from cultures with different attitudes towards consent.	Helps those who are nervous about speaking to a doctor or taking medication.
 Establish need for, and promote interpreter and translation services.	Refugees and asylum seekers. People with communication needs.	Helpful for anyone for whom English is not a first language or for people who struggle to communicate verbally.
 Check whether patients can read or write.	Participants from gypsy and traveller communities.	Aids those who have difficulties with literacy.
 Employ visual aids in addition to verbal communication.	People with communication needs.	Enables people to absorb information and understand it better.
 Provide information for people to take away (such as leaflets) and offer these in other languages.	People with limited English. Participants from gypsy and traveller communities.	Assists those with low literacy levels or those who require help from others to translate information.
 Allow patients time to ask questions or to raise queries.	Carers. People detained by the state or undergoing compulsory treatment.	Reassures and portrays involvement in decision making.
 Ask the patient how much he or she would like the person with him or her to be involved.	Carers. People with relatives living in care homes.	People attending with others may desire full involvement or only partial.
 Provide written overview of what is discussed in consultations.	People with mental health conditions which affect their capacity.	Would act as an aide-memoire which would be particularly useful for those with memory problems.
 Cater for people with visual and hearing impairments (e.g. audio information, verbalising others' presence, digital signage).	People with communication needs. People living in care homes.	Allows patients who are blind and/or deaf to still be able to use information and helps to reassure them.

3. SUPPORTING PATIENT DECISION MAKING

CHAPTER

SUMMARY

- Patients are generally **very positive about being given choices** about their healthcare by doctors.
- There was general agreement that being given choices about healthcare is a **basic human right** and **helps patients feel in control**.
- Across all groups, participants expressed a **desire for the doctor to be involved** in the decision making process and for them to **provide some steer**.
- However, patients are happy to be given **less choice in serious situations**, when the doctor's opinion is greatly valued, **or conversely, when prescribing routine medication**.
- Some participants, particularly those who belong to cultures with different attitudes towards consent, referred to **complimentary and alternative therapies** and **private (and possibly non-NHS) treatments** when speaking about the importance of being given choice and being presented with different options.
- Whilst some patients feel **confident that doctors speak about the risks and benefits** of a treatment, others think that this **does not happen enough**, or in enough detail.
- It is **less common for doctors to go through the risks and benefits in GP appointments** or when doctors are prescribing 'straightforward' medication. **This is more common when a patient requires surgery** or when the treatment being proposed can have serious side-effects.
- Patients are **generally positive about the time they are given** to make decisions about their healthcare.
- Patients tend to feel **under pressure to make decisions when a new medication is being proposed** to them, they are in an emergency situation **or they are being seen by a GP**, within a 10 minute appointment.
- When delivering bad news, doctors should consider **timing** and the **mental state** of the patient and should **involve family** members and **utilise other members of the healthcare team**.

MAXIMISING A PATIENT'S ABILITY TO MAKE A DECISION

Participants were asked their views about how much choice doctors should give to patients.

Contrary to what participants said about wanting the doctor to steer and, for some, to make the final decision, people are positive about being presented with the options and given choice. Assuming the patient (or their representative) understands, they should always be given choice.


Patients, carers and relatives commonly talked about how choice is:

- **a basic and necessary human right** - to not give choice and/or to push people into making a choice is unethical.
- **important in making patients feel in control** – of their own bodies and the decisions that they make.

People also talked about how the onus on the patient to make the final decision removes any possible later **blame on the doctor**, and results in the patient having to 'live with the decision' if they made it.


Benefits of choice and options

- ✓ Patients feel they **know their bodies and what is best** for them.
- ✓ Presenting options **offers transparency** around what is, and is not, on offer.
- ✓ Choice allows **patients to feel empowered** when making decisions that affect them.
- ✓ Being presented with the options gives the **patient peace of mind** that they have made an informed decision.

 *[When discussing a case study] I think that it was good that he gave [the patient] a choice, after all, you can't make someone have something if they didn't want to."*
(Young adult)

Downsides to choice and options

- ✗ Choice could **overwhelm** some.
- ✗ If the **situation is complex, people may not understand** the options or be able to establish what is best for them.
- ✗ Patients may could **make the wrong choice**, if left to decide themselves.
- ✗ Patients may make decisions **without feeling fully informed**. This may occur, for example, when a doctor does not have time to outline the pros and cons of each available option.


 *[Patients] get what they want and they need it to feel they are in control of their life."*
(Person with communication needs)

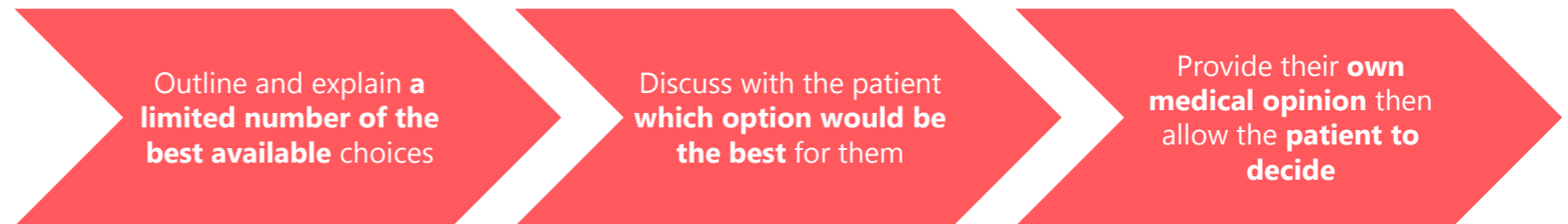
DOCTOR'S INVOLVEMENT WHEN PRESENTING THE OPTIONS

It was common for people, across all groups, to express a **desire for the doctor to always be involved and to provide a steer**, when presenting options to patients. The steps that people thought doctors should take are summarised in the diagram to the right.

People are **keen to receive a small range of the most suitable options**, rather than to be given a long list of all possible options.

Some people also felt that **it is important that doctors do not bombard patients with options all at once**. Rather, it is best to stagger options and explain that they are doing so. In other words, 'let's try this option first and then if that doesn't work we can try something else', as suggested by a participant.

 ***A limited choice of the best options is good. I could easily imagine being swamped by too many options.***
(Informal carer)



DOCTOR'S INVOLVEMENT WHEN PRESENTING THE OPTIONS

There were some common circumstances, however, that were reported where people thought it was **less necessary for doctors to provide patients with options and choice:**

- When **prescribing routine medication.**
- When it is clear that the patient is in **real need of a treatment or procedure**, for example if they require knee surgery to continue to stay mobile.

And in two other specific circumstances people feel **that doctors should not provide patients with any choice:**

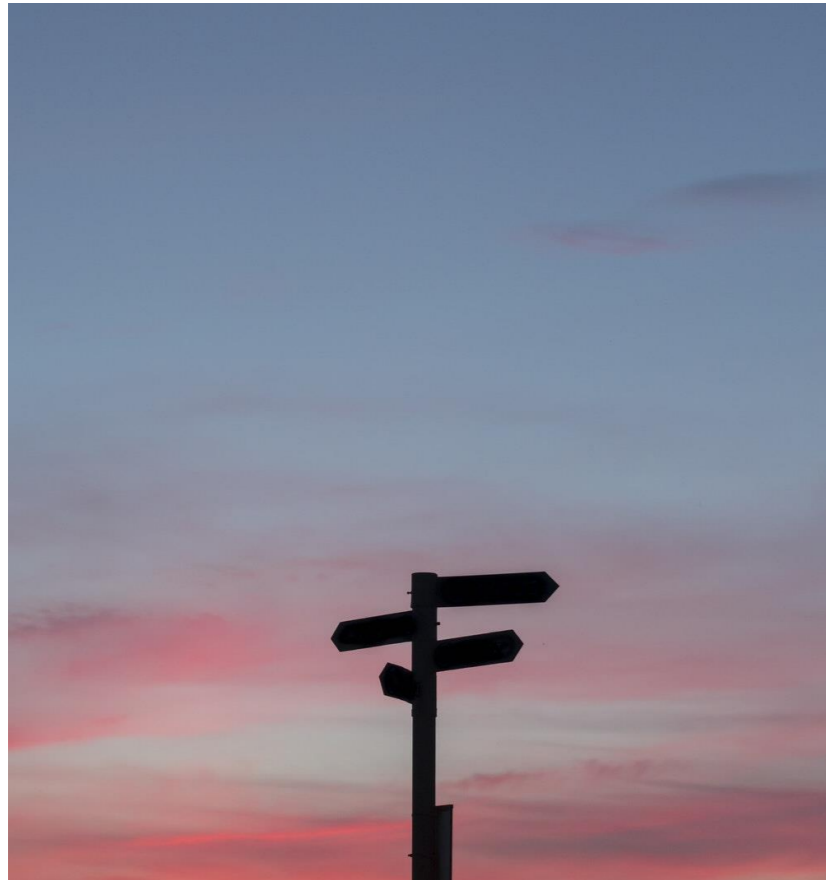
- When the situation is **life threatening.**
- In **situations where the patient's own actions are detrimental to their health** – for example, where it is advisable that the patient should stop smoking.



Participants from gypsy and traveller communities

- Tend to not to want choice and prefer to be heavily advised, or even told, what is best for them.
- Participants from this community recognised that without an explanation of the benefits and harms and a steer from the doctor, there is a risk that they would make a decision based on old wives tales and misperceptions.

WHAT DIFFERENT OPTIONS AND CHOICE MIGHT LOOK LIKE



When speaking about the importance of being given choice and presented with the different options, some people (particularly those from cultures with potentially different attitudes towards consent) referred to either:

- **Complimentary or alternative therapies or treatments** – which may or may not be provided by the NHS, and considered alternatives to drugs, for example acupuncture for insomnia and the ketogenic diet for epilepsy.
- **Private treatment, outside of the NHS** – which people would have to pay for, but might be an attractive option to some.

However, some acknowledged that although desirable for doctors to offer these kinds of alternatives, **it is not always possible for them to** as they are restricted by standards and organisations like NICE.

There was also a minority view, not specific to a particular group, that **NHS finances restricts choice** and that **doctors might withhold options that are too expensive.**

Case study – the importance of genuine choice

John and his wife care for their son James, who has multiple and complex health conditions. Although John and his wife do not have LPA, they are looking into this and for now remain very involved in big decisions about their son James' care and treatment. John reported an occasion where they were very happy to be given some options and a choice over their son James' treatment for epilepsy.

James had received medication that had not previously had the desired effect and so the consultant explained that there was an option to try him on a special diet, rather than to change to a new drug having tried a few that had not worked. John reported genuinely feeling as though this was a real choice because receiving the diet treatment involved going to a hospital in another county, hence they knew that the consultant involved would have had to get approval from his own hospital to have James treated elsewhere.

DISCUSSION OF RISKS AND BENEFIT BY DOCTORS

Patients' experiences were mixed in terms of whether or not they have experienced **receiving the possible risks and benefits** by doctors, including an outline of the possible **side effects**. There were some who said that doctors usually do go through this with them, however this tends *not* to happen when:

- Doctors are **prescribing 'straightforward' medication**.
- Patients **see a GP**.


However, people reported experiences of **doctors going through the risks and benefits for more serious treatments or procedures**, and these tend to be in hospital settings, for example:


- **Surgery**.
- **Treatments that have serious side effects**.


There is recognition that doctor's lack time to go through all of the possible side effects, however people do think that **it is important that doctors find some way of outlining the possible risks**, particularly around **side effects**.


Some, for example people from the gypsy and traveller community, suggested that **patients should ask if they want to know about these**.

There were reports of some negative experiences where side effects had not been explained and patients had experienced them, and this had caused alarm and worry.

 *They don't really [go through the possible side effects], I find out the side effects the hard way.*
(Bengali male)

 *It's their job to inform you of any side effects of any treatment you may receive.*
(Young adult)

 *I can't remember a time when a doctor has explained [the risks and benefits] to me.*
(Person with limited English)

 *They don't really [go through the possible side effects]. They just give you drugs and that's it.*
(Person with a health condition affecting their mental capacity)

VIEWS ABOUT AMOUNT OF TIME FOR DECISION MAKING

Participants were asked how they feel about the amount of time they are given by doctors that they see, in general, to decide about their treatment or care.

Views about the amount of time patients are given to decide about treatment or to make a decision are **generally quite positive**.

Where people reported experiences of feeling under pressure, this was where:

- **a new medication was being proposed.**
- **where an emergency operation was needed there and then.**

People report that **they often feel under more time pressure** to make decisions **within a ten minute GP appointment**.



I think you get a nice amount of time with the doctors, I've never been rushed or hurried [to make a decision]."
(Female from the gypsy and traveller community)

Time constraints on a GP of 15 minutes is tricky. Going to the neuro people you have so much more time."
(Person with health condition affecting their mental capacity)

DELIVERING INFORMATION THAT MAY DISTRESS PATIENTS

Participants were asked what they think a doctor should do if they think that the patient is going to be distressed by the information they are giving them about their treatment or care.

People suggested that doctors should:

- **Consider their timing of their delivery** – for example if it is a time of year for celebration (i.e. Christmas), as well **as the mental state of the patient** receiving the information.
- **Always involve the patient's family, or a carer** – either by informing them first and/or asking that they are there when the information is delivered.
- **Utilise other members of the healthcare team** – who can either assist where the doctor may lack time, or may have better skills and/or experience in the delivery of such information.

Relatives of people living in care homes

- Agreed the family should be involved before the patient is told.
- Some thought that the patient might not even need to know – for example if it was terminal and they are old anyway.

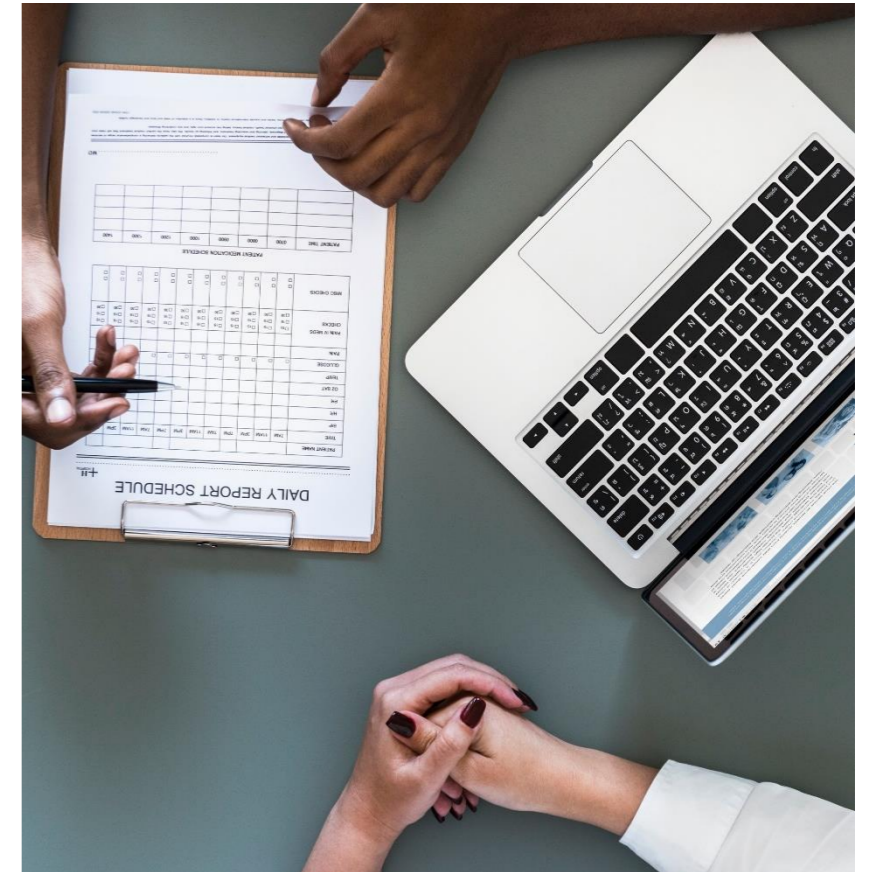
♥ *If I was a doctor and I wasn't good at that, [bedside manner] I would try and have someone else in there with me. I'm not sure that it's that easy to teach."*
(Informal carer)



4. PARTNERSHIP IN DECISION MAKING

CHAPTER SUMMARY

- Patients tend to want to **be very involved** in making decisions about their healthcare.
 - However, they **value the expertise of doctors** and often rely on them to give **a clear steer** in the decision making process.
 - Some people do not feel as involved in the decision making process as they would like to be. This can be attributed to a **lack of time in consultations, not being provided with enough information** and a feeling that **doctors do not listen** to them.
 - Whilst some patients feel **confident to raise issues or concerns**, others are **worried about time constraints** or fear **coming across as arrogant**.
 - Patients say that **feeling listened to** by a **friendly and welcoming doctor** can help them be confident enough to raise issues or ask questions.
- **Using different formats of information** could help involve patients more in making decisions about their healthcare e.g. people with limited English say they find written information useful because they can share it with a friend or family member who can help to translate it.
 - **Use of translators or interpreters** in consultations, and clear advice on how to access these services, would significantly help to involve patients, particularly those with limited English or communication needs.



DESIRED INVOLVEMENT IN DECISION MAKING

Participants were asked how much involvement they would generally like, overall, in decisions about their treatment or care.

Patients want to be very involved in decisions about their healthcare and treatment. They want to feel **informed about the risks and benefits** of treatment, and given the opportunity to **discuss options and ask questions**.

However, patients commonly want **doctors to have 'the final say'** because they are the medical professionals – their **expertise is valued**.

Some feel that they should be **more involved in 'big' decisions** (e.g. life or death scenarios). However, others feel they should be **less involved in such decisions**, as it is in these situations when medical knowledge is most valuable.

People with limited English

It was common for people in this group to suggest that in life and death situations the doctor should act quickly and with less involvement from patients and their families.

People with health conditions affecting their capacity

- The desired level of involvement can depend on the patient's state of mind at the point of treatment.
- The desired level of involvement can be low when patients have greater trust in doctors to make the 'right' decision on their behalf.

Participants from gypsy and traveller communities

- Would like a very clear steer from the doctor when deciding about their treatment or care.
- However, they would still like to be as informed as much as possible.

Relatives of people living in care homes

- Want to be most involved in decisions when a new treatment is being proposed or their relative encounters a serious medical issue. They are happy to be less involved in decisions about common ailments e.g. the treatment of a urinary tract infection, or a medical issue that their relative has encountered previously.
- However, they want to be aware of all decisions being made. In part, because they are often the only factor that remains "constant", when doctors and the environment can change regularly.



I trust my doctors, not myself to steer anyway."

(Person with a health condition affecting their capacity)



The facilities were changing, the doctors were changing... I am the only one who knows what's happening."

(Relative of a person living in a care home)

ACTUAL INVOLVEMENT IN DECISION MAKING

Whilst some participants expressed being happy with their actual level of involvement in decision making, others would like to be **more involved** than they currently are.

Not **feeling listened to**, or not being provided with enough **information** due to **time constraints** can result in patients feeling inadequately involved.

When patients are not as involved as they would like to be, they feel as though they **lack control**.

People with limited English

- Language barriers minimise opportunities to be involved in the decision making process.
- Some feel that they have no choice but to follow the advice from doctors because they struggle to understand information or articulate their opinions.

Case study – struggling to communicate

Miremba has limited English proficiency. She struggles to communicate with healthcare professionals and as a result feels powerless in the decision making process. She is positive about the NHS but feels totally at the mercy of doctors because of the language barriers. She also does not know what healthcare she is entitled to. Miremba says, "I have no power and no education."

People who have experienced detention by the state or compulsory assessment/treatment

- Do not feel as involved as they would like to be.
- Do not receive adequate information or explanation about their treatment.
- Feel that they completely lack control, which is described as being uncomfortable and confusing.
- Suggest that patients should be allowed to make the small decisions (e.g. what food to eat and when), given that control over bigger decisions (e.g. what medication to take) is not within their control.

CONFIDENCE IN RAISING ISSUES AND CONCERNS

Many patients feel **comfortable and confident** raising issues or concerns with doctors.

Others worry about **time constraints** and not wanting to be seen to be **wasting doctor's time** or **taking too long** in an appointment.

Familiarity with a doctor and their general **attitude** can affect patients' confidence to raise issues (e.g. patients feel more comfortable when their doctor is **friendly**).

When patients think or assume that they will not be **listened to**, they can be reluctant to raise issues or concerns with doctors.

Trust in **doctors as the experts** can act as a barrier to patients speaking up. **Fear of appearing arrogant** can also act as a barrier to patients raising issues or expressing concerns.

Young adults

- Age can prevent these patients from being confident to raise issues and concerns. In part, because some of those we spoke to think doctors will assume they are ignorant.
- The topic of the consultation can affect how confident young people feel to raise concerns (e.g. they are less comfortable when talking about reproductive or sexual health).



I always get nervous talking about those things [sexual health] and I feel really awkward."

(Young adult)



I feel very comfortable... though busy [doctors] take their time to look back through my history and answer questions."

(Young adult)



BARRIERS TO INVOLVING PATIENTS AND HOW THESE COULD BE IMPROVED

Barriers	Suggested solutions
Restricted time	<ul style="list-style-type: none"> • Longer appointments where at all possible. • The opportunity to speak over the phone after appointments. • Receiving a document about how to prepare for a consultation to ensure that the limited time can be used effectively.
Limited use of different types of communication	<ul style="list-style-type: none"> • Written information to take away after appointment. This can be particularly useful for those who need help from others to understand or remember their conversations with doctors, e.g. people with limited English, Participants from gypsy and traveller communities (among whom there is a low level of literacy) and people with memory problems. • Use of visual aids for those who struggle to understand written English, e.g. those who have low levels of literacy or capacity issues. • Use of interpreters or translators for those with communication needs or limited English, including clear information on how to access the service.
Doctors' attitudes	<ul style="list-style-type: none"> • Friendly, warm and welcoming behaviour helps patients feel comfortable and to generally 'open up.' • Being explicitly asked by the doctor whether they have any questions or concerns.
Lack of continuity of care	<ul style="list-style-type: none"> • Regularly seeing the same doctor.



The first [suggested improvement] would be the way they welcome you."

(Person with limited English)



[10 minute appointments] are not enough for me to explain... to put something across when it is not your first language."

(Refugee)

ACKNOWLEDGEMENTS

Ipsos MORI would like to thank the team at GMC for their help with this study. We would also like to thank all of those who participated in the research and shared their views with us – including patients and the public and the stakeholders. Without their contribution, this research would not have been possible.



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