



Ipsos MORI
Social Research Institute

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Exploring patient and public attitudes towards medical confidentiality

Findings from Discussion Groups and In-depth Interviews

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Contents

Executive Summary	5
Direct care uses and disclosure	5
Indirect care uses and disclosure	6
Non care uses and disclosure	6
1 Introduction	1
1.1 Background	1
1.2 Research aims and objectives	1
1.3 Methodology	2
1.4 Presentation and interpretation of the data	4
1.5 Structure of the report	4
1.6 Acknowledgements	4
2 Direct care uses and disclosure	6
2.1 Implied consent to disclose information for direct care purposes	6
2.2 Sharing information with, and receiving information from, those close to the patient	8
2.3 Disclosing information about patients who may be at risk of serious harm	11
2.4 Managing and protecting patient information	13
3 Indirect care uses and disclosure	18
3.1 Sharing information for indirect care purposes	18
3.2 Anonymised and de-identified information	20
4 Non care uses and disclosure	25
4.1 Requests for information from employers, insurers, government bodies and others	25
4.2 Disclosing information in the public interest	27
5 Conclusion	33

Appendix A: Confidentiality: draft guidance for consultation (see separate document)

Appendix B: Confidentiality: long questionnaire, short doctor questionnaire, short patient questionnaire, explanatory statements (see separate documents)

Executive Summary

Executive Summary

The General Medical Council (GMC) is the independent professional regulator of doctors in the UK. As part of its responsibilities, it publishes guidance to doctors on the principles of confidentiality and respect for patients' privacy that they are expected to understand and follow. In 2014 the GMC published draft guidance, and ran a public consultation on this between November 2015 and January 2016 (see Appendix A). Responses on the draft guidance were sought from doctors, patients and members of the public, and organisations and others involved with health and social care via a number of questionnaires (see Appendix B).

In December 2015 the GMC commissioned Ipsos MORI to undertake research with some groups of individuals who may be less likely to take part in a formal written consultation:

1. Older people (age 75+), especially those in residential care
2. Young people (between the ages of 15 and 17)
3. People from black and other minority ethnic groups
4. People from Gypsy and Traveller communities
5. Asylum seekers and refugees
6. People with health conditions that may affect their mental capacity (e.g. mental health issues, or dementia)
7. People who have experienced detention by the state (e.g. in prison or in hospital under the Mental Health Act)
8. People who have experienced domestic violence
9. People who have rare medical conditions
10. People who are proposing to undergo, are undergoing or have undergone a process (or part of a process) of gender reassignment.

The aims of the research were to explore a number of key themes/issues around doctors' responsibilities around confidentiality and explore expectations around how doctors should treat patient information. The findings from this research will be considered as part of the wider consultation.

Throughout January and February 2016, Ipsos MORI spoke to 86 people in a series of discussion/focus groups, and individual in-depth interviews about their views on patient confidentiality.

Direct care uses and disclosure

One of the specific aims of the research was to explore the circumstances in which participants feel it is reasonable for doctors to rely on **implied consent for sharing patient information** within the healthcare team for direct care purposes. Participants were comfortable with doctors relying on implied consent when sharing relevant information, though some

were less comfortable with administrative staff and receptionists having access to medical information. Participants' views on the conditions that need to be met when relying on implied consent reflect those set out in the draft guidance.

Another aim was to explore what considerations doctors should have when **sharing information with a patient's family or friends**. Similarly there were strong levels of agreement with the draft guidance. Participants felt it was important for a doctor to listen to friends and family members' concerns, however they differentiated this from disclosing information about the patient; in most cases they felt the patient's consent was required before doing this. When the patient in question is under the age of 18, it was felt that age and maturity were important considerations for doctors when deciding whether to share information about them with their family members.

Participants were also asked about their expectations around **whether information should be shared without consent about adults who are at risk of serious harm**. On the whole, participants agreed that doctors need to act in the patient's best interests if the patient is in danger and lacks capacity. However, when a **patient has capacity to consent** participants were more split. Some found it difficult to justify why a doctor might need to disclose information about a patient without their consent if they are capable of giving it. Others could recognise that there may be circumstances in which there is need to do so, even where nobody else (other than the patient) is at risk of harm.

The research also explored cases where **patient information might be shared unintentionally** by doctors and the people they work alongside. Participants' main concerns were around confidential information being accidentally shared with staff or members of the public not involved in direct patient care, for example notes being left open on computer screens; other patients or public overhearing conversations; and information being sent to the wrong recipient, via email for example. Reflecting the draft guidance, participants felt responsibility lay with the doctor to take extra steps to reduce the risk of these mistakes happening.

Indirect care uses and disclosure

The research also looked at patient and public **expectations about how their information is used for indirect care**, for example for health and social care management or research. Participants were able to recognise a number of benefits which might come about as a result of using patient information in this way such as improving services, addressing budget constraints, or becoming better informed about diseases, treatments and drugs. Participants were, on the whole, comfortable with the use of their own (anonymised) data for these purposes, with the condition that the reason for its use was communicated with participants in advance of use.

The use of **anonymised, or de-identified, information** was an absolute requirement among participants. Participants understood the process of anonymising data and were comfortable that others working on behalf of doctors could perform the process of de-identifying information. However some participants felt strongly that 'blanket' consent for records to be used anonymously should be sought at the time a patient registers at a practice. Where there is still a risk that data could be identifiable, participants argued that doctors would need to take extra steps beyond removing identifiers to ensure that they had patient consent to use the data.

Non care uses and disclosure

The final aim of the research was to explore patient and public expectations about non care uses and disclosure of information. This includes the **disclosure of medical reports to third parties**, such as employers or insurers. In line with the draft guidance, participants felt that doctors should **offer to show reports to patients** before they are sent to the person or

organisation who has commissioned the report. This would allow patients to check for and request changes to any factual inaccuracies.

When discussing the **disclosure of information in the public interest**, participants thought it was reasonable for a doctor to share patient information if others were at risk of harm. Specifically, participants were in agreement with the GMC's draft guidance around reporting concerns to the DVLA or DVA, reporting serious communicable diseases, and reporting gunshot and knife wounds. On the whole, it was felt that a doctor's responsibility to protect the public, other patients or colleagues would sometimes excuse a breach in patient confidentiality.

Across the discussion groups and interviews there were high levels of trust in doctors to act in the patient's best interests and according to a patient's wishes wherever possible. However, on the whole participants agreed that doctors were sometimes justified to go against a patient's wishes if they or someone else was at risk of harm. Importantly, there were strong levels of agreement throughout the research with the principles outlined in the draft guidance.

Introduction

1 Introduction

1.1 Background

The General Medical Council (GMC) is the independent professional regulator of doctors in the UK, whose purpose is 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 legal power to give advice to doctors on standards of professional conduct, performance and medical ethics. To that effect, it publishes guidance which set out the ethical principles and professional standards that must underpin good medical practice. *Good Medical Practice* is the core guidance issued to doctors and is supported by a range of explanatory guidance expanding on the higher level principles, for example *Confidentiality*. The latter, published in 2009, lists the principles of confidentiality and respect for patients' privacy that doctors are expected to understand and follow. The GMC is committed to reviewing its guidance regularly to ensure it is up to date, relevant and reflects the issues that doctors face. It began the process of reviewing its guidance on confidentiality in late 2014, with the aim of publishing a revised document at the end of 2016.

As part of this review, the GMC published draft *Confidentiality* guidance (see Appendix A), and carried out a public consultation of the issues raised within this with doctors, patients, members of the public, and organisations and others involved with health and social care via a number of questionnaires (see Appendix B). The aim of the entire consultation was to seek views on what kinds of patient information should be shared and disclosed by doctors, to whom (other healthcare professionals, family members, third parties) and under which circumstances.

1.2 Research aims and objectives

Alongside this wider consultation, the GMC commissioned Ipsos MORI to undertake research with groups who may be less likely to engage in the formal written consultation process, be more likely to experience barriers in accessing healthcare, and/or have issues with mental capacity (including giving informed consent). These groups were defined as follows:

1. Older people (age 75+), especially those in residential care or their carers/decision makers to be present or act on their behalf
2. Young people (between the ages of 15 and 17)
3. People from black and other minority ethnic groups
4. People from Gypsy and Traveller communities
5. Asylum seekers and refugees
6. People with health conditions that may affect their mental capacity (e.g. mental health issues, or dementia) or their carers/decision makers to be present or act on their behalf
7. People who have experienced detention by the state (e.g. in prison or in hospital under the Mental Health Act) or their carers/decision makers to be present or act on their behalf

8. People (both men and women) who have experienced domestic violence
9. People who have rare medical conditions
10. People who are proposing to undergo, are undergoing or have undergone a process (or part of a process) of gender reassignment (referred to hereafter as transgender individuals).

The aim of this research was to explore a number of key themes/issues that the draft *Confidentiality* guidance covers, to seek the views of patients and the general public around whether they agree or disagree with the underlying principles in the guidance and to explore expectations around how doctors should treat patient information. More specifically the research aimed to elicit considered views on the following aspects of the draft guidance:

- a) The circumstances in which it is reasonable for doctors to rely on **implied consent for sharing information within the healthcare team about patients for direct care**, and which other healthcare professionals/members of staff it is reasonable for them to involve (i.e. how wide should the 'healthcare team' be/ who could be included here).
- b) What considerations doctors should have when **sharing information with a patient's family or friends** about their condition or treatment.
- c) Patient and public expectations about **whether information should be shared without consent about adults who are at risk of serious harm**, even where the patient has refused permission for information about them to be shared.
- d) Patient and public **expectations about how their information is used for indirect care** – i.e. reasons other than their direct care, for example for health and social care management or research.
- e) Patient and public expectations about the **disclosure of medical reports to third parties**, such as employers or insurers.

1.3 Methodology

To meet these research aims, a mixed method approach was adopted, consisting of **discussion/focus groups**, including two conducted online, and **individual in-depth interviews**. Fictional case studies were used to stimulate discussion, designed to further explore the core principles within the draft *Confidentiality* guidance such as sharing information with, and receiving information from, those close to the patient.

Not all case studies were used within all group discussions and depth interviews; rather they were chosen to explore issues suspected to be especially pertinent to certain groups because of reasons related to 1) cultural and/or religious background, 2) gender and/or age, 3) enhanced privacy concerns, either because of specific personal circumstances/history or distinctive characteristics which could make people more identifiable within 'anonymised' data, and 4) having a specific role in a patient's life, for example being their carer.

The method (group discussions or in-depth interviews) was chosen with the audience of interest in mind. Where appropriate, discussion groups of 8 people were held, allowing individuals to be exposed to the circumstances, views and opinions of others which may challenge their own views. Smaller groups (with around 6 attendees) were recruited for

certain groups of interest as it was felt a large group might overwhelm participants. For some groups of interest, it was deemed more appropriate to discuss the issues individually because individuals might find a group dynamic difficult and/or because the issues discussed could be particularly sensitive. Therefore in-depth interviews were chosen accordingly.

Participants were recruited through a mixture of face-to-face recruitment channels, via snowballing, and via gate-keepers such as charitable organisations and support groups. Recruitment screeners, participant information leaflets, and consent forms were provided to participants where appropriate, and were developed alongside Ipsos MORI's Ethics committee to ensure they were suitable and appropriate for the target audience. All participants were offered a financial incentive as a thank you for taking part. More details on the research method, method of recruitment and location is detailed below:

	Group of interest	Location	Method of recruitment	Research method
1	Older people living in care homes	Leeds	Gate-keeper	Discussion group (6 people)
2	Carers	Rural Wales	Face-to-face	Discussion group (8 people)
3	Young people (1st group)	Newcastle	Face-to-face	Discussion group (8 people)
4	Young people (2nd group)	Belfast	Face-to-face	Discussion group (8 people)
5	People from black and minority ethnic groups	Manchester	Face-to-face	Discussion group (8 people)
6	Gypsies and Travellers	South East England Rural	Face-to-face	2 discussion groups (6 people in each)
7	Asylum seekers and refugees	London	Gate-keeper and snowballing	Depth interviews (6 people)
8	People with mental health problems and/or their carers	South East England	Gate-keeper and snowballing	Depth interviews (6 people)
9	People who have experienced detention by the state	Scotland	Gate-keeper	Depth interviews (6 people)
10	People who have experienced domestic violence	London	Gate-keeper and snowballing	Depth interviews (6 people)
11	People with rare medical conditions	England, Scotland, Northern Ireland & Wales	Face-to-face and gate-keeper	Online group (6 people)
12	Transgender people	England, Scotland, Northern Ireland & Wales	Gate-keeper	Online group (6 people)

Participants were recruited to ensure that a range of demographic characteristics were represented within each group of interest including gender, age, and social grade. Groups were carried out across the UK and in rural and city locations.

1.4 Presentation and interpretation of the data

It is important to note that 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 intended to be illustrative rather than statistically representative of a wider population and, as such, does not permit conclusions to be drawn about the extent to which findings can be generalised to the 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 and the truth as they see it.

1.5 Structure of the report

The report is structured around the GMC's consultation questions, which asked patients, the public, doctors and healthcare professionals for feedback on the draft guidance *Confidentiality* (see Appendix A). This includes questions asked in the long questionnaire, the shorter questionnaires, and the explanatory guidance questionnaire (see Appendix B).

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

1. **Direct care uses and disclosure:** These are uses of patient information that directly contribute to the diagnosis, care and treatment of an individual. See paragraphs 36-80 of the draft guidance.
2. **Indirect care uses and disclosure:** These are uses of patient information that contribute to the overall delivery of health and social care, but which fall outside the scope of direct care. Examples include health services management, research, epidemiology, public health surveillance, education and training. See paragraphs 81-109 in the draft guidance.
3. **Non-care uses and disclosure:** These are uses of patient information that are not connected to the delivery of health or social care but which serve wider purposes. These include disclosures for public protection reasons and for the administration of justice, and for purposes such as financial audit and insurance or benefits claims. See paragraphs 110-132 in the draft guidance.

The data from group discussions and depth interviews were thematically analysed and the report presents the findings across all groups where areas were explored. Where there were any differences in opinion or experience by group, these are drawn out and discussed within each of the three chapters which follow.

1.6 Acknowledgements

Ipsos MORI would like to thank the team at GMC 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.

Direct care uses and disclosure

Paragraphs 36-80 in the draft guidance

2 Direct care uses and disclosure

Chapter Summary

Research participants were comfortable with doctors relying on implied consent when sharing relevant personal information within the healthcare team, though some were less comfortable with administrative staff and receptionists having access to medical information.

They described a number of conditions that need to be met when doctors are relying on implied consent, which chime with those set out in the draft guidance.

There was a good level of agreement with the principles outlined in the draft guidance around doctors' responsibilities when sharing information with, and receiving information from, those close to the patient. For example participants raised the importance of doctors listening to family members and friends, whilst respecting patient wishes about what information should be disclosed with whom. Participants agreed, however that doctors need to act in the patient's best interests if the patient is in danger and lacks capacity.

On the whole participants (both parents and young people themselves) raised age and maturity as important considerations for doctors when deciding whether to share information about a person under the age of 18 with their family members.

Whilst some participants found it difficult to justify why a doctor might need to disclose information to protect patients who have capacity without their consent, others could recognise that there may be circumstances in which there is need to do so even where nobody else (other than the patient) is at risk of harm.

Participants' had some concerns about information being unintentionally shared with the wrong people, for example other patients or public overhearing conversations, or information being sent to the wrong recipient via email. Reflecting the draft guidance, participants felt responsibility lay with the doctor to take extra steps to reduce the risk of these mistakes happening.

2.1 Implied consent to disclose information for direct care purposes

As stated in the draft guidance, the usual basis for sharing information for direct care is the patient's consent. Consent can be either *explicit* (or expressed) or *implied*, where it is reasonable to infer that a patient agrees to the use of the information, even though this has not been directly expressed. Implied consent was explored with all groups except those with rare medical conditions.

2.1.1 Relying on a patient's implied consent to share information about their direct care

Although when some participants first started talking about implied consent there was some discomfort with the idea, there was recognition that there will be situations where it is impractical for doctors to ask for explicit consent. For example to avoid unnecessary paperwork, or the lengthy task of needing to collect consent for all involved and for every information sharing episode.

There was a near universal acceptance of doctors sharing information with other medical staff or other healthcare professionals working within the healthcare setting, or NHS more generally. There was often the assumption that this is what happens anyway in reality and is necessary to enable doctors to provide the best care and to avoid putting patients at risk. Whilst some included administrative staff and receptionists here, others however were far less comfortable with doctors relying on implied consent to disclose information about a patient with these.

Participants listed five conditions that need to be met when doctors rely on implied consent to share relevant information within the healthcare team. These largely chime with those set out in the draft guidance:

1. The person receiving the information is doing so on a 'need to know basis' – it needs to be relevant to their job and they need to have involvement in the direct care of the patient
2. Information is available to patients about the process – covering what happens in practice, how much information might be shared with whom and how patients can withdraw their (implied) consent if they wish to. Participants raised the importance of patients being given the opportunity to discuss implied consent with their doctors
3. Where the patient has objected, this must be observed
4. Those receiving the information understand how to treat it – they have signed confidentiality agreements and have received training on how to keep information secure and respect this
5. Where there is a direct benefit to the patient and/or to other patients in similar situations

2.1.2 Expectations around doctors relying on implied consent to disclose relevant information to the healthcare team

Participants were asked whether they would expect doctors to rely on implied consent when sharing information with a number of different people, in much the same way as Q2 in the short questionnaire:

- **Reception and administration staff** – As already noted, opinions were mixed with some participants stating that they would expect (and be comfortable with) doctors relying on implied consent. Others were comfortable with some information being shared with these (for example name and address information) but not medical information, without direct consent, whilst others said 'No' to implied consent altogether. Reasons given were lack of trust, fear of being judged and a higher risk of information being leaked.
- **A pharmacist** – Participants were generally accepting of implied consent here on the basis that pharmacists would hold the patients name and address anyway, and have details of medication on their own systems.
- **A social worker** – Participants were less comfortable with implied consent here, reporting that they were unsure whether a social worker would be as clear about confidentiality (compared to those in the healthcare setting), and might not act in the person's best interest. This view, however, was not universal and some said 'Yes'.

- **A nurse who is part of the direct team** – Implied consent was, on the whole, acceptable here.
- **A nurse who is not part of the healthcare team** – Whilst some thought implied consent was probably ok (they work within the NHS and are likely to be using the information for the benefit of the patient and/or other patients or for the hospital directly), others questioned the relevance of use of personal information here.

In the online group with transgender individuals, the following case study was used to explore the principle of implied consent further:

Harriet has come into hospital for a foot operation. Harriet met with the consultant, Prof. Matthews, a month ago to discuss the procedure, and told him that she was currently undergoing gender reassignment, including having surgery to change from male to female.

After the operation, whilst Harriet is still under general anaesthetic, a nurse arrives to escort Harriet back to the recovery ward. The nurse talks to Prof. Matthews about how the surgery went, so she can understand Harriet's immediate care needs and a bit more about Harriet's medical history.

Do you think it is appropriate for Prof. Matthews to reveal Harriet's gender history to the nurse?

Participants were generally in agreement that it would not be relevant for the nurse to be told about the patient's gender history. They questioned the relevance of this to the aftercare of a foot operation, unless the nurse would need to assist the patient to use the toilet during their stay. When asked about the problems that could arise if the doctor did reveal the patient's gender history to the nurse, participants mentioned the risk of transphobic discrimination and that the patient might miss out on specific treatments.

2.2 Sharing information with, and receiving information from, those close to the patient

The draft guidance highlights the significant role that those close to the patient can play in supporting and caring for them, and the importance of acknowledging that role. We were able to explore views on doctors sharing information with, and receiving information from, family members, friends or carers with 1) participants from Black and Minority Ethnic (BME) backgrounds, 2) people with experience of mental health problems, 3) those with caring responsibilities, 4) young people aged 15-17, 5) people from Gypsy and Traveller backgrounds, 6) those who have experienced domestic violence, 7) those who have experienced detention by the state, and 8) asylum seekers or refugees.

There was a good level of agreement with the principles outlined in the draft guidance across all groups:

- Doctors should, and need to, **listen to a patient's family members or friends to encourage their role in caring for the patient**. Doctors should take their concerns on board and then make a (private) decision on whether any action is required.
- However, doctors should not discuss the patient's information with family, friends or carers without prior consent to do so. **Doctors need to respect patient's wishes about what information is disclosed** with whom and should establish with their patients who they can discuss information about them with. This is crucial as doctors will not necessarily know the details of a patient's relationships with their family members (or others).

- Doctors should act in the patient's best interests **if the patient is in danger or their life is at risk** (for example they are unconscious or undergoing a life threatening procedure) – **or if others are at risk**, for example if the patient has an infectious disease.
- Doctors should be able to share information about a patient with those close to the patient if the **patient lacks the capacity** to make their own decisions.

Other considerations that individuals from certain groups raised, which are not necessarily stated specifically in the draft guidance, were:

- The need for **doctors to take special care when deciding whether to share information with family members of patients from certain cultural backgrounds**. An example given was being Muslim and in relation to sexual health, sex and pregnancies outside of marriage. This was raised in both an interview with an Asylum seeker/refugee and in one with a person with experience of domestic violence.

"Culture is important so I am a Muslim and if I got pregnant outside of marriage then the family is going to be very disappointed and there is going to be a lot of negativity."

Asylum seeker / refugee interview

- The need for **doctors to be aware that whilst women and men from Gypsy and Traveller communities might be comfortable with doctors sharing information with family members from the same gender, this may not be the case for doctors sharing information about women with men, and vice versa** (Gypsy and Traveller discussion groups).

The following case study was used across all groups (except the group with those with caring responsibilities and young people) to further explore the sharing of information with those close to the patient:

Sarah and Liam are worried about their father, David, who suffers from depression. David has been on long term medication for this, however recently they have become worried that he is becoming unable to look after himself and may cause himself harm. David feels there is no problem however.

For reassurance they contact David's GP to discuss his medication and raise their concerns for his wellbeing.

How should his GP respond to them?

The majority of participants thought the GP should allow the patient's children to voice their concerns about their father, however when doing so the GP should receive the information and not divulge anything (assuming he is not informed about the family relationship, and has not sought David's prior consent to do so). The GP should suggest to the patient that he talks to his children.

Some participants, however, were of the opinion that the GP *should* talk to the children about David, assuming he had not explicitly expressed his desire for the doctor not to do so, on the basis that the GP's primary concern should be the patient's wellbeing.

The following case study was used in a discussion group with people with caring responsibilities.

Brenda is a part time carer for Jeremy, who is in a wheelchair and suffers from multiple long term health conditions. Brenda has recently become concerned that Jeremy's medications are causing excessive drowsiness, but he refuses to see a doctor, saying that he's just not sleeping well.

She contacts his GP to discuss the side-effects of Jeremy's medication, and whether anything else could be causing the symptoms.

What should the GP do?

The general feeling amongst those with caring responsibilities, was that it would not be necessary for someone in Brenda's situation to know the medical history of the person they care for, unless not knowing puts them (or others) at risk. Some expressed that it can sometimes be useful to have some information about the people you care for, and others acknowledged that it would be difficult for a carer if they were to witness someone becoming unwell and not be able to do anything about this. In this situation, however, it was assumed that the doctor would need the patient's consent before discussing the patient's health with their carer.

2.2.1 Sharing information about those under the age of 18 with other family members

In parts of the study, where parents of children and young people were involved, we were able to explore a parental view of doctors sharing information about those under the age of 18 with their family members (and notably their parents/guardians). Participants varied greatly in relation to their view on the age at which a young person's medical information becomes their own private business and should not be shared, without consent, with their family members. There were some parents who expressed that this would depend on both the age and the maturity of the child.

"I think it depends how mature your child is. Whether your child is childish or sorts things out. Bit of both age and maturity"

Participant from the BME group

Another point, raised by some parents in one of the Gypsy and Traveller groups, in relation to children's patient confidentiality, was around the importance of this for children who are being abused at home by their parents. It was noted that a doctor might be the person that a young person goes to, to seek help, and so their privacy would need to be observed in such cases.

The following case study was used in the two discussion groups with young people:

Carol's daughter, Emma, is 15 and is in a long term relationship with a boy her own age. Carol expects that Emma has started having sex with her boyfriend, and wants to make sure Emma is using contraception. However, she thinks Emma will find it too awkward to discuss this with her. Instead, Carol talks to their GP to confirm that Emma knows the options available to her and is practising safe sex.

How should the GP respond?

Young people were split in relation to their view on whether the GP should speak with the mother of the 15 year old about her sexual behaviour:

- Some expressed that under the age of 16, a child might not be aware what is best for them and it *would* be appropriate for the doctor to speak with the parent about issues such as contraception; whilst,
- Others felt that the doctor *should not* divulge anything to the parents of a child who is age 15, assuming the doctor did not think that the patient was at risk of harm and the patient had not already given their permission for the doctor to do so.

There appeared to be a subtle gender split on this: with girls being slightly more likely to express the importance of a 15 year old's patient confidentiality in such a situation, however there were still girls who felt that the doctor should tell the girls' mother so this view was not universal.

The young people involved were in agreement that at age 16, when a person is legally allowed to have sex, their medical and sexual health should be their own business, and should not be discussed with others (including their parents) without their consent.

2.3 Disclosing information about patients who may be at risk of serious harm

The draft guidance stipulates that doctors should usually respect the wishes of adult patients who are able to make their own decisions, even if those decisions leave them (but nobody else) at risk of death or serious harm. However, the draft guidance suggests that in exceptional cases there may be circumstances in which information can be shared without a patient's consent, even if the patient is capable of making his or her own decisions and nobody else is at risk of serious harm.

Views on this revision to the guidance were explored in interviews with 1) people who have mental health problems, 2) those who have experienced domestic violence, and 3) those who have experienced detention by the state.

Broadly participants agreed that it is not always preferential, or practical, for doctors to seek consent before sharing information about a patient if they lack capacity, for example when a patient is unconscious. When a patient does not lack capacity however, and assuming they are conscious, participants were more split:

- Some participants found it difficult to justify why a doctor would disclose information without a patient's consent if they were able to give it. They felt that the patient's wishes would always need to be prioritised even if that left them at risk of harm. Even in cases where the patient was at suicide risk, for example, they felt that it was the patient's choice to seek help from authorities or family members.
- However others recognised that in some cases it would be in a patient's best interest for the doctor to disclose information about them. Examples given included protecting a patient from the risks of suicide, drug abuse, or depression.

The case studies used in this part of the discussion further highlight this divergence in opinion.

The below case study about a patient at risk of suicide, was used among participants who have experienced detention by the state:

Elias is currently being held in an immigration centre in the UK and is soon to be deported back to Brazil where he comes from. Dr Haines works at the immigration centre and has recently treated Elias and fears that he is at risk of suicide. When Dr Haines raised these concerns with Elias, Elias admitted that he had been feeling really low and had been having suicidal thoughts. Dr Haines asks Elias for his permission to contact his GP in the UK to talk to him about Elias' previous history, however Elias refuses as he is worried that Dr Haines will share the information with the immigration authorities.

What should Dr Haines do? Should he respect Elias' wishes, or go ahead and contact his GP?

In this scenario, participants agreed that as Elias' life might be at risk, it was not an option for the doctor to do nothing even if that meant disclosing information without his consent. They therefore felt that it was in Elias' best interests for the doctor to contact the GP to discuss his treatment, while reassuring Elias that the immigration authorities would not be involved.

The following case study about violence in the home was used in interviews with people with mental health problems:

Dr Bennet has just seen a female patient, Natalie, who came in complaining of a high temperature and sore throat. While Dr Bennet was examining Natalie, she noticed severe bruising over Natalie's neck and back. When she asked her about this, Natalie admitted that her husband can sometimes get angry and violent towards her. Natalie hasn't talked to anyone about this before, and is not willing to go to the police.

What should Dr Bennet do in this situation?

One participant felt that the doctor has a duty of care towards the patient and therefore needs to report what he has seen to the police regardless of whether he has obtained the patient's consent. However, this was the exception, and participants largely felt that Dr Bennet should not disclose information to any authorities, including the police, without Natalie's consent.

Instead, participants felt that it was Dr Bennet's responsibility to encourage Natalie to seek support, but that intervening or reporting the situation to the police or other support groups was a risk in such a sensitive scenario; this was a decision that Natalie alone needed to make. They therefore felt that the doctor's involvement had to stop at providing information to Natalie about further support available. Participants also felt it was important to document the incident so that if the situation deteriorated, there would be a record.

Whilst participants could justify disclosure in Elias' situation (the patient in the first case study), and because his life may have been at risk, it was far more difficult for them to do in Natalie's case (the patient in the second case study). Although Natalie's life could also be at risk, participants did not mention this and instead focussed on how:

- The doctor should not come between a relationship
- The doctor could exacerbate the situation (and the patient's husband may become more violent towards her)
- Natalie may not want to leave her husband.

Finally, participants who had experienced domestic violence were presented with a case study on a GP's responsibilities when working with social care professionals:

Kate lives next door to John, who lives on his own. Kate is concerned about John because the last few times she has seen him, he looked like he had not been washing and keeping up with personal hygiene. She also noticed that John had lost a lot of weight, suggesting that he may not be eating well or may be ill.

Kate phoned social services to say she was worried about him, and a social worker visits John. John refuses to engage with her, and also tells the social worker not to contact his GP because it's none of her business. However the social worker does contact John's GP to ask him to attend a meeting to discuss what support could be given to John.

What should the GP do?

In this scenario participants felt strongly that it would not be an option for the GP to take no action. Participants distinguished between the doctor listening to the social worker's concerns, which many felt was acceptable, and disclosing information about the patient to the social worker, which was not felt to be necessary. The majority felt that the GP should listen to the social worker's concerns, take them on board, and contact John directly to encourage him to get support.

It was suggested that no decisions should be made about the patient's care package or treatment based solely on the information provided by the social worker, or without the patient's consent. However, reflecting the complexity of the issue, participants were not in agreement; one participant felt strongly that the GP should not meet with the social worker as he does not have the patient's consent to do so.

2.4 Managing and protecting patient information

Often improper disclosure of patient information is unintentional. For example, it may be the result of conversations in reception areas which are overheard or notes and records which are seen by unauthorised staff which have not been managed securely. The draft guidance advises doctors that they must make sure any personal information about patients that they hold or control is protected at all times against improper disclosure. In particular, the draft guidance recommends that they should not:

- leave patients' records, or other notes they make about patients (whether on paper or on screen) unattended, or share passwords;
- share personal information about patients where it can be overheard (for example in a public place or an internet forum);
- access patient's personal information unless they have a legitimate reason to view it.

2.4.1 Improper access and disclosure

Patient information is understood by participants to be stored on electronic databases and/ or in paper records. However, there was **little certainty amongst participants about the exact ways that doctors are able to share information**. Broadly

participants suggested information could be shared via emails, letters, texts, phone calls, face-to-face appointments, passing on of patient records (paper and electronic) and in meetings.

Across participants there was a **degree of trust in the way that doctors handle their information**. It was generally assumed that doctors would ensure data safety and would have rules and protocols to prevent improper access and disclosure (2.4.2 explores storage in more detail). Indeed some participants were unable to provide example scenarios involving improper access/ disclosure of patient information and instead provided positive examples (which meet the draft guidance's advice) to show why they were not concerned:

'In a busy hospital, the doctor usually takes you to a side room to discuss things in private.'

Asylum seeker /refugee interview

However, despite there being a degree of trust, the majority of **participants were able to outline certain situations where they were concerned about the potential for unintentional, improper access of patient information**. Largely mirroring the scenarios the draft guidance provides advice for, the key examples participants identified as a concern for them included:

- **Staff and public not involved in direct patient care having access to documents** which have been left out on desks or up on screens;
- **other patients and public overhearing** discussions about a patient's information; and
- (not highlighted in the draft guidance) **sending patient information to the wrong people**.

In discussions relating to improper access of patient information by staff and public not involved in direct patient care, participants tended to focus on receptionists overhearing discussions between doctors and patients. Although, it was also mentioned that receptionists, along with cleaners and temporary staff, have access to desks which may have patient records on them or have records up on computer screens which can then be read.

Across participants it was common for people to have had an experience where they felt that their personal medical information could have been heard by others. Most common was for participants to have had receptionists ask them loudly about their reason for an appointment in a busy reception area. However, others were able to suggest where they were concerned with the doctor's actions, such as, having conversations about their health in hearing distance of other patients or being able to hear doctor/ patient conversations through closed curtains on hospital wards.

In addition to the scenarios already covered by the draft guidance, participants also discussed scenarios involving data errors which could lead to improper access and disclosure. Top of mind for a number of participants was errors around medical letters being sent to the wrong address, potentially allowing people who know the patient to be privy to their personal information. Further reflecting a move to more electronic processes in medicine, participants also talked about electronic storage and transfer issues. For example, some participants talked about their information going on to shared databases which were more widely accessible to just those who provide direct care. While an older participant living in a residential care home suggested that there were already instances of electronic records being mismanaged. This participant referred to an instance where doctors provided patient information to a pharmaceutical company which were intended to be anonymous but due to an error in provision were sent records containing identifiable information.

Consequently, electronic management systems and doctors handling of these are also a key area participants identified as a potential risk for improper access and disclosure.

In all the above scenarios participants expressed concern with having patient information potentially accessed and disclosed in this way. In particular they were fearful of people who they have a relationship with or who know them, finding out information about them that they would not want known. As such, and as outlined in the draft guidance, these were scenarios where they felt it was **important for doctors to take extra steps to reduce the risk of information being shared improperly**.

2.4.2 Records management

Following on from thinking about when information may be improperly accessed and disclosed, participants were asked what measures they felt should be in place to prevent the various scenarios from happening. Participants were in broad agreement with the draft guidance around doctors' responsibilities in relation to the management of patient records.

Reflecting paragraph 142 of the draft guidance, participants felt that doctors should take a number of steps to **ensure that they have conversations which are about patient information in a private area**, where they are sure that they cannot be overheard by others:

'Verbal conversations need to be conducted privately rather than on a busy ward and patients given the option to be talked to in a private room.'

Mental Health interview

To prevent those without a direct need to know from viewing patient information, **participants also made a number of suggestions around limiting access to patient information which largely mirror paragraph 141 of the draft guidance**. Suggestions included, ensuring that screens are locked when not at a desk; having computer screens facing in a way which is not in direct view of others; having short sleep times on computers; password protecting documents; having the right security software loaded on computers; and being organised and filing notes away so that they are not left out unattended on desks.

However, moving into the draft guidance on record management and retention, for all participants, to guarantee that the appropriate action was taken to ensure against improper access and disclosure, **it was felt that adequate training and confidentiality agreements were needed**. Participants put forward that the training would need to cover all the processes outlined above and would need to be provided to all members of staff (including doctors). Along with training it was expected that the staff at the beginning of their contracts would sign a confidentiality agreement which could be used to hold them to account. This sentiment by participants sits closely with paragraph 148, which states that staff should be trained and understand their responsibilities to protect confidentiality. For a number of participants, it was felt that the training should happen on a regular basis, to ensure that staff continued to be aware of data protection procedures and any changes. It was suggested that this could happen at a minimum every 6 months and could be done in-house. One older participant, in a retirement home, also suggested that inspections should take place to encourage good practice.

The need for training was something that came out strongly for participants when discussing a case study example where a receptionist, when not at the computer in reception, had been leaving patient records open on his screen:

Dr Bain has been a GP in a small practice for ten years. Joseph works on the reception and has been working at the practice for over two years. Dr Bain discovers that Joseph has been accessing patient medical records to check if they are eligible for a flu jab, and leaving patient records open on his computer screen when not at the reception desk.

What should Dr Bain do, if anything?

Initial reactions to the case study were mixed. A number of participants felt strongly that Joseph should not have had access to the medical records in the first place. These participants were more likely to say that Joseph should have his access removed, be given a disciplinary or be sacked. For the male Gypsy and Traveller group and the older people living in a retirement home, it was particularly felt that Joseph had broken patient confidentiality and should consequently be fired.

Participants were also more likely to agree with this view if Joseph had been told about patient confidentiality on starting the job. However, many more participants expressed a more sympathetic stance towards Joseph. In all cases, aligned with the draft guidance (paragraph 148), it was felt that it was the doctor's responsibility, as the direct carer of patients, to ensure that Joseph understands what he did wrong and is given the appropriate support to ensure that he does not make this mistake in the future.

'It's their [the doctor] patient's records. Doctors should have a duty of care even with their records. Even if they are not treating them they still have a duty to ensure patient confidentiality.'

Participant in younger persons group

Participants felt that the **doctor should communicate with Joseph about what he has done wrong**, highlighting the importance of patient confidentiality. Some felt it would be appropriate at this point for the doctor to issue Joseph with a warning and suggested that if Joseph was found to be doing it again then the disciplinary action taken should be more serious.

Along with communicating to Joseph his error, as mentioned earlier, nearly all participants felt that it was **important that the doctor arranged for Joseph and potentially other members of staff be given training** to ensure that all staff in the future are aware of patient confidentiality and what protocols exist to ensure this. In Joseph's case it was felt that training would assist him in understanding why it was important for him to ensure that he came out of the patient records when finished and/ or lock the computer when not sat in front of it.

By providing training and being very clear with new staff, as soon as they begin at a practice, what the confidentiality protocols are, it was felt that doctors would ensure that in the future practice staff have no doubt about what they are legally required to do and so reduce the risk of future improper access and disclosure of patient information.

Indirect care uses and disclosure

Paragraphs 81-109 in the draft guidance

3 Indirect care uses and disclosure

Chapter Summary

Participants were able to recognise a number of benefits which might come about as a result of the use of patient information for indirect care purposes. For example to improve services; to address budget constraints; to become better informed about diseases, treatments and drugs; and to help plan health and social care services for future generations. Participants were, on the whole, comfortable with the use of their own data for these purposes.

However there was a consensus that the use of (anonymised) data for indirect purposes could only be justified if the reason for its use was communicated with participants in advance of use.

The use of anonymised, or de-identified, information was an absolute requirement among participants, and participants understood the process of anonymising data (i.e. removal of names and other potential identifiers).

Where anonymised information was going to be used, some felt strongly that 'blanket' consent to do so should be sought at the time a patient registers at a practice, which would cover all future uses. Alongside this, doctors should communicate with patients around the reason for their medical records to be used for research, or others, purposes.

Where anonymised information was being used for indirect care purposes, but where there is still a risk that data could still be identifiable, participants argued that doctors would need to take extra steps beyond removing identifiers to ensure that they had patient consent to use the data.

Participants agreed that others, working on behalf of doctors, could perform the process of de-identifying information (for example people employed to do so) however the doctors would be responsible for ensuring that this is done safely and securely.

3.1 Sharing information for indirect care purposes

In some cases patient information can be used for indirect care purposes, for example to help with overall delivery of care, beyond the direct care of an individual patient. As the draft guidance suggests, the health and social care system would be unable to plan services, conduct research or be publicly accountable for the services it provides without some information about patients.

Indirect care uses and disclosure was discussed in the discussion groups with people from black and minority ethnic backgrounds, Gypsy and Travellers, transgender individuals, people with rare medical diseases and older people living in residential care. In each group, participants were given the example of an NHS hospital providing a private data company with patient information on numbers of patients attending A&E. The patient information provided by the hospital has been anonymised:

An NHS hospital asks a private data company to analyse data to understand why there has been a recent increase in the numbers of patients attending A&E.

They want to understand:

- the reasons patients attend A&E and how this has changed over time; and*
- what kinds of patients are most likely to use A&E, for example by age, gender, health status, service use.*

They want to use this information to improve services outside of A&E, to try to reduce the numbers being admitted to hospital in future.

The NHS hospital provides the company with a set of completely anonymised patient records (those which do not include patients' names, addresses or dates of birth).

In your opinion, is the hospital doing the right thing by patients/in the public interest?

When initially discussing the use of patient information for the purpose of indirect care and in particular the case study, nearly all participants indicated that they would be happy to have their data used in this way. Indeed they were able to suggest a number of benefits which might come from the use of patient data for indirect care purposes which included:

- improved services;
- better ability to address budget constraints;
- better awareness and understanding of diseases, which in turn leads to better treatment and drugs; and
- better health and social care planning for future generations.

For a number of participants, particularly those in the older group, it was already believed that their data was frequently being used for indirect care purposes. They suggested that they thought a number of organisations were already doing this:

'This isn't a new problem, they gather statistics every week. It's a routine exercise. Your name isn't with the statistics, x number of patients have heart disease for example.'

Participant in the older people group

However, participants did have some concerns about the risk of their personal data being shared more widely than just the stated indirect use, be it a clinical or service need. There were concerns that their details might become identifiable and used to discriminate against them, to 'cold call' them or for identity theft. Consequently, for the majority of participants they suggested that they would have **little resistance to the use of their information for indirect care purpose provided that it had been communicated to them that their information would be used in this way, before it being used, and that their information was kept anonymised.** The next section will explore this in more detail.

3.2 Anonymised and de-identified information

When sharing patient information for indirect care purposes, the draft guidance advises doctors that, whenever possible, they should disclose either:

- data where it is impossible to identify patients; or,
- data where personal identifiers have been removed, but there is still some risk that patients could be identified unless appropriate controls are in place.

Those in the rare medical conditions group and transgender group were asked about their views on anonymised and de-identifying information. In both groups the advice outlined above was something that all the participants showed strong agreement with. It was felt that **patient information should be kept anonymous or at a minimum have names removed**. For many they would only feel comfortable having their data used for indirect care if it was anonymised.

Participants were asked to consider a case study with a practice providing medical records of diabetic patients to a research company exploring risk factors associated with diabetes. Participants were told that the patient's names, addresses and dates of birth were removed from the records before they were passed on.

Jane, the Practice Manager at Green House Medical Centre has received a letter from a research agency carrying out a NHS research study looking at some of the risk factors associated with diabetes. Jane discusses the request with the doctors at the surgery, in a confidential meeting, to check whether they are happy to share a set of diabetes patient records. As long as the records are anonymous, it would not be necessary or practical to ask all of the diabetes patients involved whether or not they are happy for this to happen.

The doctors question the relevance of patient's names, addresses and dates of births for this research and agree to pass on a set of completely anonymised patient records (i.e. those which do not contain patients' names, addresses or date of births), for some of their diabetes patients to the researchers.

The doctors agree to the request, given that the research is likely to advance knowledge around the causes of diabetes which is a good thing.

In your opinion, are the doctors doing the right thing by their patients/in the public interest?

All participants were in agreement that the doctors in the scenario had done the right thing by removing the name, address and data of birth of participants. **The removal of the patients' details was understood by all to represent the anonymising of the data**. However, echoing paragraph 89 of the draft guidance¹, a number of the participants also felt that alongside anonymising/ removing personal identifiers, the **doctors also had a responsibility to their patients to communicate that they would be sharing the patients' information in this way**. As one participant said:

¹ 'You [doctors] should be satisfied that patients have been given information about how their information may be used – for example, in a fair processing or privacy notice.' Para 89, Confidentiality: draft guidance for consultation. GMC

'I agree that this is appropriate. However, I'd expect some sort of communication from doctors periodically (yearly, biannually) to state exactly what information is shared and how they'll deem it appropriate when to share my data, and who with.'

Participant in the rare medical conditions group

A number of participants thought the key way that doctors could inform them was by sending a letter. Importantly, it was felt by participants that in these communications the **doctors should provide patients with a convincing reason for why their medical records were needed for the study.**

In the transgender group, and also when discussing indirect care uses more generally with the BME group, it was **felt by some that their consent should be sought even when the data were anonymised or personal identifiers removed.** These participants acknowledge that it might be difficult to gather consent every time data are disclosed for indirect care uses, however it was believed that at a minimum patients should be asked when originally registering at a practice if they would consent to have their data used for indirect care purposes. They suggested that there should be a document provided to patients which outlines what the patient would be happy for the doctors to share in the future.

The notion of consent was also drawn on when participants were asked to consider if their position on the scenario would change if the doctors had provided data showing patient's NHS number and/or had been asked to provide information on a much smaller group of individuals, for example patients who have a specific rare disease. In these scenarios the participants expressed concern that individuals would still be identifiable even when personal identifiers were removed and that some patients may not be happy with people being able to link medical history back to them. As such, it was argued that **where the chance of data being identifiable was increased, doctors would certainly need to take extra steps beyond removing identifiers and to ensure that they had patient consent to use the data.**

A final point of discussion around the case study shown above was how participants would feel if, instead of a research company, their information was being provided to either an insurance company or a drug company. In these scenarios, many participants struggled to see why these companies, particularly insurance, would need to use their data for indirect care purposes. Consequently, a number said that they would not be comfortable for doctors to provide any form of information to such companies:

'I don't see how an insurance company will in any way improve patient outcomes. I would object to sharing data in this way'

Participant in the transgender group

Even where participants said they would be happy for anonymised data to be disclosed, this concern about the use of the data was also evident. Indeed, participants felt strongly that in these settings the doctors would have to undertake detailed quality checks on the companies and have a valid reason for sharing the data which was clearly and openly communicated to patients. Because of the uncertainty around legitimacy of data use, as with the context of a smaller and more unique sample of patients being disclosed, they also felt in these contexts that consent from patients should be obtained.

3.2.1 The process of anonymising or de-identifying information

Paragraph 88 of the draft guidance states that information may be anonymised or de-identified for indirect care uses by a person who provides (or supports the provision of) direct care to the patient. However, if this is not practicable it may be undertaken by someone who is incorporated into the healthcare team and who is bound by legal and contractual obligations of confidentiality.

Participants were asked to comment on how they would feel if the removal of personal identifiable data was performed by someone outside of those directly providing the patient with care. Participants were shown the case study below and asked to comment:

In order to anonymise the diabetes patient records for the research agency, Green House Medical Centre is required to remove the identifiable information from the individual records. Unfortunately the doctors are not able to do this, because they are too busy in their clinics. Jane (the Practice Manager) brings in Sue, who works in the administrative team, on a temporary basis to support the healthcare team. Sue has received training and understands her legal and contractual obligations of patient confidentiality.

For the majority of participants their views on who should be involved in the process of anonymising or de-identifying information were broadly in agreement with the draft guidance. **On the whole it was felt acceptable that if the doctors were unable to remove the identifiable information themselves then they could employ someone on to their team to help them with this.** Like the guidance, the participants felt that the practice had a responsibility to ensure that anyone brought in to remove the identifiable information had **signed a confidentiality agreement** where at a minimum they would be sacked if they failed to comply. They also felt that it was important that this person be **supervised adequately** by permanent members of the team, in the case of the scenario above, the practice manager. These steps were felt to help to ensure that patient confidentiality is maintained. However, again reflecting the draft guidance, the bringing of people from outside the practice in to help with the work was felt to **only be something the practice should do if absolutely necessary.**

While on the whole participants were happy for people to be brought in, it is important to note that because of concerns about the management and protection of patient information, there were some who did not feel comfortable with having anyone other than those directly involved in the patient care remove identifiers from patient information.

As well as the scenario discussed above, patients were also asked how they would feel if the data were de-identified by the research agency conducting the research. While no participants immediately said that they would be comfortable with a research agency doing this, views were mixed on if this was at all permissible. Some participants suggested that they would feel more comfortable if the staff working at the research agency had experience in ensuring that data were kept confidential and were bound by ethical standards. Before a research company began this process it was felt that patients would need to be told this was happening and given the appropriate reassurances, along with the opportunity to opt out.

However there were others, who when considering the possibility of the research agency having experience, still felt uncomfortable with patient information being de-identified in this way. For these participants it was felt the onus should very much be on the practice to ensure that personal details were not included in the information being sent over to the research agency and that the research company would not have the appropriate experience or legislation behind it to

support doing this work. This was compounded by a concern that the research company would not have the same accountability as the practice.

Overall therefore, in line with the draft guidance, when patient information is to be shared for indirect care purposes, participants felt that in the first instance it is for doctors to ensure that the data are anonymised and that they are very clear and open with patients that they may be using their data for such purposes.

Non-care uses and disclosure

Paragraphs 110-132 in the draft guidance

4 Non care uses and disclosure

Chapter Summary

Research participants agreed with the draft guidance on disclosing information to third parties such as employers or insurers, and felt that doctors should offer to show reports to patients before they are sent to the person or organisation who has commissioned the report, unless one or more of the conditions set out in the guidance applies. This would allow patients to check for and request changes to any factual inaccuracies. However, participants felt that patients should not be able to change other information within the report as this would be deceptive and unfair.

When discussing the disclosure of information in the public interest, participants thought it was reasonable for a doctor to share patient information if others were at risk of harm. Specifically, participants were in agreement with the GMC's draft guidance around reporting concerns to the DVLA or DVA, reporting serious communicable diseases, and reporting gunshot and knife wounds.

On the whole, it was felt that a doctor's responsibility to protect the public, other patients or colleagues would sometimes justify a breach in patient confidentiality.

4.1 Requests for information from employers, insurers, government bodies and others

Non-care uses and disclosures cover a wide range of purposes, including disclosures for public protection, the administration of justice and for purposes such as financial audit and insurance claims. In this research we focused on disclosures to third parties such as employers and insurers, and disclosures for public protection reasons.

In some cases, doctors are asked to write reports about patients for employers, insurance companies or similar purposes, so that they can make an informed decision about the patient. We explored participants' views about whether doctors should offer to show these kinds of reports to patients before they are sent off to the report commissioner.

Whilst the majority of participants did not have any experience of this, several had had a report sent to their employer. In most cases their doctors had either shown them the reports before they were sent off, or the patients were copied in when the reports were submitted.

Paragraph 112 of the draft guidance suggests that doctors, when considering whether to disclose information for non-care uses, should offer to show their patient, or give them a copy of, any report they write about them for employment or insurance purposes before it is sent, unless the following factors apply:

1. The patient has already indicated they do not wish to see it.

2. Disclosure would be likely to cause serious harm to the patient or anyone else.
3. Disclosure would be likely to reveal information about another person who does not consent.

Broadly speaking, all participants agreed that doctors should offer to show reports to patients before they are sent to the person or organisation who has commissioned the report, unless one or more of the conditions set out in the draft guidance applies. The majority also thought that doctors should seek a patient's explicit consent before disclosing identifiable information for purposes other than their care provision or local clinical audit. However, whilst participants wanted doctors to share information with them before it was submitted, they did not think that patients should be allowed to edit the report following their review. This will be explored in further detail throughout the chapter.

Despite their views aligning with the section on *Disclosing information for employment, insurance and similar purposes* in the draft explanatory statement draft guidance, there was a slight degree of uncertainty regarding the process. Several participants were unaware that patients could have access to and read their reports, and consequently questioned whether this genuinely happened. However, this was only expressed by a few participants who had no previous experience of this.

Disclosure of information to third parties was discussed with participants with experience of mental health problems, with rare medical conditions, and those who have experienced domestic violence and detention by the state. In each case, participants were given the example of a woman (Samantha) who has applied for life insurance after buying a house. The insurance company requests a report on Samantha's health status from a doctor, who agrees and completes the report.

Samantha is 35 and has applied for life insurance after buying a house. Before any policy is agreed upon, the insurance company appoints a doctor to write a report on Samantha's health status, including providing details of her medical history. The doctor agrees and completes the report.

Should the doctor offer to show the report to Samantha before sending it to the insurance company?

The majority of participants thought that the doctor should offer to show the report to Samantha before sending it to the insurance company, and did not deliberate on this. They felt that the patient in this situation has a right to see what is included in their report, and if the information is not transparent then they might not necessarily know how their personal information might have affected their application.

They also thought that the doctor should not necessarily 'tell on' patients, but accepted that there were circumstances in which it would be acceptable for an employer to request access to someone's medical information, particularly if anything that affected an employee's ability to work. Participants with rare medical conditions had had direct experience of this, but had always had sight of any report or correspondence between their employer and doctor.

The theme of reviewing and editing a report was widely discussed across all interviews and groups when exploring this case study. In the draft explanatory statement guidance section on *Disclosing information for employment, insurance and similar purposes*, paragraph 10, it states:

'If a patient asks you to amend a report, you should correct any errors of fact and any opinion that is based on errors of fact. You should not remove information, opinion or advice if you believe the report would be false or misleading.'

Participants primarily agreed with this statement; the majority believed that the patient should have the right to see a report to check for any factual inaccuracies and request edits if there were mistakes; however they should not be able to change any other information, as this would be deceptive and unfair. People believed that reviewing reports for errors was very important as a mistake could have a major consequence on the patient's life, if left unresolved.

"Samantha should be shown the report as it may be inaccurate and you may need to challenge it. Doctors are human and make mistakes that may need correcting. You have a right to challenge facts about YOUR health."

Participant in the rare medical conditions group

Participants also reiterated the importance of only including relevant information in the report to make it specific to what the company is asking for. This is in line with the draft guidance stated within paragraph 116.

There was a strong feeling across all relevant groups that the patient should always give consent for the information to be given and to be copied in when the report is sent, regardless of whether they wish to see it or not. Whilst a few participants stated that the patient doesn't necessarily need to be sent the report if they had previously told the doctor they do not wish to see it, many thought that they should still receive the report and could decide at the time whether to read it or not.

4.2 Disclosing information in the public interest

The draft guidance advises doctors that sharing information can be a public interest if:

- It will protect individuals or society from risks of serious harm, such as serious communicable diseases or serious crime.

The draft guidance also advises doctors to seek the patient's consent before disclosing personal information in the public interest. If consent is refused then doctors should take the following aspects into consideration before deciding whether disclosure is justifiable:

- The potential harm or distress to the patient arising from the disclosure.
- The potential harm to trust in doctors generally.
- The potential harm to others if the information is not disclosed.
- The potential benefits to an individual or to society arising from the release of the information.
- Whether the harms can be avoided or benefits gained without intruding into the patient's privacy or, if not, what is the least significant intrusion.

On the whole, participants agreed with these principles. They thought it is reasonable for a doctor to share patient information if other people were at risk of harm. It was commonly mentioned that the safeguarding of children and other people should be the most important factor when sharing patient information in the public interest.

Carers expressed the view that the patient must be put at the centre of each decision, and only essential information should be shared on a 'need to know' basis. Additionally, they thought that the health and safety of the carer should be taken into consideration; the doctor should tell them about the patient's condition if they thought it could impact their own safety and wellbeing.

We used the following examples to explore disclosure in the public interest, which are all included in various sections of the draft explanatory statement guidance:

- Patients' fitness to drive and reporting concerns to the DVLA (Section A)
- Disclosing information about serious communicable diseases (Section D)
- Reporting gunshot and knife wounds (Section E)

4.2.1 Reporting to the DVLA

The following case study was explored with participants with experience of mental health problems, from Black and Minority Ethnic (BME) backgrounds, with caring responsibilities and older people living in residential care:

Geoff works as a taxi driver, but hit his head in a recent fall caused by fainting. He goes to see his GP, who asks him if fainting is common, and whether he regularly feels dizzy or light headed. Geoff says that he does, but he hasn't actually fainted until the time he hit his head.

His GP arranges some tests, but is there anything else he should consider?

Participants were mindful that the patient's livelihood was at stake when discussing this example. On the whole they placed a lot of trust in the patient himself to take responsibility, and not to drive while waiting to find out if the problem is serious in nature.

"Geoff has to be responsible for not driving until the test results come back. That doctor must explain and stress the importance of Geoff not driving. You hope that self-preservation and a concern for his passengers and other drivers should guide it".

Mental Health interview

Participants agreed with the advice provided in the section on *Patients' fitness to drive and reporting concerns to the DVLA or DVA* in the draft explanatory statement guidance. There was an overall consensus that the DVLA should be informed about this, but opinion was divided on whether or not it was the driver's or GP's responsibility to do so. Participants did think it was crucial that the doctor should inform the patient of their legal responsibility to report conditions affecting driving to the DVLA. If the patient disclosed to a GP that while waiting for test results they were not going to stop driving, then the GP should have the right to tell the DVLA, echoing the section on *Patients' fitness to drive and reporting concerns to the DVLA or DVA*, paragraph 8 of the draft explanatory statement guidance.

Others took the view that the patient could be putting himself and others at risk, and if this is not looked into further then the doctor could be seen as negligent and held accountable if other people were harmed as a result. They quoted the Glasgow bin lorry crash as an example of where this went wrong.

Although this was one of the more difficult case studies for participants to think about, and because the patient's livelihood could be damaged, generally they veered towards the doctor having the responsibility to inform the DVLA. They were concerned that contacting the DVLA would distract doctors from their daily routine, but at the same time they understood that doctors had the responsibility to do so.

4.2.2 Disclosing information about serious communicable disease - Sexually transmitted disease

In the discussion groups and interviews with people from BME backgrounds, young people aged 15-17, from Gypsy and Traveller backgrounds and those who have experienced domestic violence, the following case study was used:

Tom has been diagnosed with an STI (Sexually Transmitted Infection) and is visiting his GP, Dr Goodman, to discuss his treatment options. Tom's girlfriend is also a patient of Dr Goodman's, and is six months pregnant. The GP tells Tom that he should discuss his diagnosis with his girlfriend, but Tom refuses as he has been cheating on her and doesn't want to upset her during pregnancy. Dr Goodman explains the risks the STI poses to his girlfriend and his unborn child if she does not seek treatment, but Tom won't reconsider.

What should Dr Goodman do?

All participants who were presented with this case study felt that the doctor in this situation should tell the girlfriend as the unborn baby could be at harm, and there was little disagreement on this. Their prime concern was the woman and unborn baby, rather than the cheating partner. They viewed the baby as not having a choice and the doctor as having a responsibility to look after the unborn child.

Participants thereby fundamentally agreed with the draft guidance stated in the section on *Disclosing information about serious communicable diseases*, paragraph 10 of the draft explanatory statement guidance. The guidance specifies that doctors should disclose information to a person who has sexual contact with a patient who has a sexually transmitted serious communicable disease, if they are at risk of infection, or if the patient has not informed them and cannot be persuaded to do so.

Although some thought that it would be a different scenario if there was no baby involved, most participants articulated that because the cheating partner has done something considered to be morally wrong, he should therefore accept that the doctor might 'tell on him'. Participants did not see any major issues with this, although certain participants were mindful of the potential extreme impacts on the patient of the GP telling the girlfriend against their wishes, such as self-harm, depression and suicide.

4.2.3 Disclosing information about serious communicable disease - At work

Participants with caring responsibilities were presented with a different case study about communicable disease at work:

Dr Coote is a GP. Her patient Julian, who works at a local care home, visits her complaining of stomach pain and nausea as well as other symptoms such as jaundice. Dr Coote suspects that he might have hepatitis C, which is confirmed by blood tests. However Julian fails to pick up his blood tests and Dr Coote is concerned that he may be putting colleagues and residents of the care home at risk by not having the appropriate treatment.

What should Dr Coote do?

Participants with caring responsibilities thought that the doctor in this situation should contact the patient to give him his results, and should be able to disclose his health condition to his employer because colleagues and residents of the care home could be at risk. They believed that doctors have a duty of care to the general public, as well as to the individual patient, and that the care home should have their own policy on how to act with this information. In this case study, disclosure without the patient's consent could be justified in the public interest, because failure to disclose the information would put colleagues and residents of the care home at risk of Hepatitis C.

They thereby agreed with the draft guidance provided in the section on *Disclosing information about serious communicable diseases*, paragraph 8 of the draft explanatory statement guidance. This states 'if a patient refuses to allow you [their doctor] to tell someone outside the healthcare team about their infection status, you [their doctor] must respect their wishes unless you [their doctor] believe that failing to disclose the information will put your colleagues or other patients at risk of infection'.

Participants exploring this case study also thought that if the patient's refusal to consent to disclosure puts others at risk of harm, and it outweighs the patient's and the public's interest in maintaining confidentiality, the doctor should disclose the information regardless of the patient's wishes. Moreover, the patient should still be informed that information is being disclosed, even if it is being done so without their consent, reiterating what is stated in Paragraph 127 of the draft guidance.

4.2.4 Reporting knife and gunshot wounds

Guidance is also provided in the draft explanatory statement guidance about reporting gunshot and knife wounds. In paragraph 3a within *Reporting gunshot and knife wounds*, the guidance states that the police should be informed whenever a person arrives with a gunshot wound or knife injury, to help 'enable them to assess the risk to the patient and others, and to gather statistical information about gun and knife crime in the area.' In these cases, the patient's personal information does not need to be disclosed when initially contacting the police. If it is practicable, the doctor should seek the patient's consent to disclose personal information, but if consent is refused or cannot be obtained, then the doctor should make a professional judgement about whether disclosing this is justified in the public interest.

Young people aged 15 - 17, those from Gypsy and Traveller backgrounds, and asylum seekers and refugees were presented with the following case study:

Dr James is a consultant in A&E/Emergency medicine in a hospital. He is treating Alex who has come in with a stab wound on his leg. Although Alex won't confirm it, Dr James is suspicious that it is the result of an attack. However, Alex says he will leave the hospital if Dr James gets the police involved.

What should Dr James do?

There was a good level of agreement with the principles outlined in the draft guidance across all groups. On the whole, participants presented with this case study thought that the doctor's prime concern should be treating the patient, and only after they had done so should they report the incident to the police. They had no qualms about this, despite it being against the patient's wishes; they trusted the doctor to thoroughly 'read' the situation and make a judgement on what would be the best action to take for the patient as well as the public.

For the majority of participants, their views on reporting knife and gunshot wounds were broadly in agreement with the draft explanatory statement guidance. They believed that reporting the incident to police would be justified in these circumstances, since it would be in the public's best interest as it could prevent potential further attacks. This aligns with paragraph 13 and 14 within the explanatory statement guidance on *Reporting gunshot and knife wounds*. Some participants claimed that they did not view this as 'breaking patient confidentiality'. Instead they interpreted this as a completely separate, practical issue of reporting a crime that anyone in their right mind would and should do.

"I totally agree with it. It's a crime when you get a knife injury, so it would be wrong if the hospital didn't inform the police."

Detention by the state interview

Most participants thought of the doctor as having 'a duty of care' to the public and the patient, and therefore should inform the police regardless of the patient's wishes. Additionally if consent to disclose information is refused, they thought the doctor should try to convince the patient that the police need to be informed.

One participant, who had previously been detained by the state, explained how they had been in the exact same situation where they didn't want their incident to be reported to the police, but their doctor had insisted. The participant understood and didn't make a fuss, stating that they wouldn't have minded if the doctor had gone 'behind their back' to inform the police, appreciating that reporting the incident actually was the correct action to take in this circumstance. Others agreed that if they were in the patient's situation, they would still expect the doctor to report the incident even if they had not given consent for them to do so.

However, several participants presented with this case study expressed the view that there could be a slight danger of the doctor jumping to false conclusions if they did not know the full context behind the attack. Therefore they thought it was essential for the doctor to obtain a substantial amount of information before going to the police, and also thought the circumstances of the attack would influence whether or not they should report it.

The issue of a mandatory report to the police was mentioned during a depth interview with an asylum seeker/refugee. They explained how it was obligatory for doctors in their home country to report an incident to the police before treating a patient, and if this procedure was not followed, then the patient would be unable to be treated. It is worth noting this was only mentioned once, yet it highlights the potential different mind-sets that could contribute to the various opinions regarding this case study.

4.2.5 Other examples where it would be acceptable for doctors to share patient information in the public interest

Participants were then asked to think of other situations where it would be acceptable for doctors to share patient information in the public arena. Across all groups, participants were able to suggest a number of examples which included:

- **Safeguarding children and other members of the public** - Where a child is concerned, participants thought doctors should have the power to inform police or social services to protect harm to the child. They also felt that doctors should 'forget the confidentiality' if another person was at risk of harm, for example if their patient has murderous intentions towards someone else, it would be the doctor's responsibility to inform the police without consent.
- **Infectious disease** – Participants thought the public should be warned in the outbreak of a contagious diseases and infections, such as Ebola, as they could be passed on.
- **Accidents and attacks** – Participants felt that sharing information about attacks and accidents, for example traffic collisions, would be beneficial, in order to direct people to a safe location. They did not see this information as being linked to an individual, but more generic.

5 Conclusion

The views expressed by those who took part in this research are largely in accordance with the core principles within the draft *Confidentiality* guidance. This suggests that the GMC's advice to doctors around confidentiality and respect for patient's privacy is in line with the way people expect doctors to act, make decisions and use their autonomy.

Few differences were observed in the way individuals from each of the groups thought about the issues, and as such this report has presented the collective views of participants across all of the different groups engaged.

Where there were differences, however, these were raised within each of the three main chapters of this report. The following points may require further reflection and could have implications for the guidance the GMC produces and/or the way in which doctors communicate with patients about patient confidentiality:

Direct care uses and disclosure:

- There were participants (across most groups) who raised discomfort with doctors sharing patient information with receptionists and other administrative staff members. This finding points to the potential requirement for doctors to emphasise the necessary role of such staff in the direct care of patients, when communicating with patients either verbally or via information posters and leaflets.
- Participants from Gypsy and Traveller communities were clear that whilst they *would* be happy for a doctor to share information with those close to them from the same gender, this would not be the case for a doctor sharing information with those from the opposite gender.
- One or two participants emphasised the importance of doctors needing to take special care when deciding to share information (and particularly sexual health) with the family members of patients from certain cultural or religious backgrounds, because of the potential negative consequences to the patient involved.
- When a doctor needs to disclose information about a patient who has capacity without their consent, even where nobody else (other than the person involved) is at risk of serious harm, participants were split. Some found it difficult to justify why a doctor would disclose information without a patient's consent if they were able to give it. This suggests that participants would expect doctors to react on a case by case basis in these scenarios.

Indirect care uses and disclosure:

- Participants from the transgender discussion group expressed a desire for doctors to collect 'blanket consent', for example when a patient registers with a GP practice, for the use of anonymised (or de-identified) data for indirect care uses. Where there is still a risk that data could be identifiable, participants argued that doctors would need to take extra steps beyond removing identifiers to ensure that they had patient consent to use the data.

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