

Crib sheet for everyone

NHS clinicians and administrators who decide which health services should (and should not) be funded

Introduction

The jury's charge is about creating new records for purposes other than direct patient care. Question 2 is about who should be allowed to access and extract data from the patient records created, and for what purposes. It lists seven potential uses and users, and the jury has to decide which of these should be allowed. In each case, the potential user wants to access individual-level data (not totals) with identifiers removed. The data is anonymised (not "personal data" in the eyes of the law) but there is still a very small risk that someone could be identified from the data they access. People will only get access to the data if they agree to handle it securely, as required by law. The users will pay for access to the data – enough to cover the costs of providing access.

For this exercise, your small group must prepare to role-play presenting *and* challenging the case for the rest of the jury for this potential use.

3 group members identify reasons why NHS clinicians and administrators who decide which health services should (and should not) be funded - should be allowed access to the patient data.

Prepare a summary of your main points on one flip chart page.

When making the case, you may like to make some of the following points:

- you need to be able to access the data to analyse what treatments and services the NHS provides in your local area, and how much they cost, and how effective these services are.
- you have a limited budget, and you need to prioritise what treatments should be provided to which patients, and how many patients will need the services.
- your job is a necessary part of the functioning of the health service, and you need access to the data to provide the evidence to prioritise funds.
- you don't gain personally, and your organisation does not get any additional funding as a result of this use of the data.
- you will provide proper protection of the data and allow access only by the people who need it.
- statistics can be helpful, but they are not flexible enough. They don't let you answer all of the questions you have in order to be able to understand the health needs of your local population, and make decisions about what services to provide and not to provide. Also, the statistics are always either about GPs or about hospitals but, unlike this new dataset, not both. For example, if you are planning what services should be provided to people with diabetes, you need to know about hospital clinics and admissions, and prescriptions of insulin by GPs.

Try to think of other good reasons for you to access the data. Prepare for the challenging questions you are likely to be asked.

3 group members identify reasons to be *skeptical* of NHS clinicians and administrators who decide which health services should (and should not) be funded being allowed access to the patient data and/or challenges that should be answered by this group. Prepare a summary of your main points on one flip chart page.

Possible challenges might include:

- How would this benefit ordinary citizens and patients?
- What do you and your organisation stand to gain from access to the data?
- Why should patients trust you with patient data?
- Why don't you use other available data, such as statistics published nationally, which give a breakdown of different services provided in different local areas?
- Why do *you* need to do this – couldn't it be done by someone else e.g. within the NHS?

You might also think about:

- how much risk there is of this organisation not protecting the data appropriately, and the potential harms or unfairness that could occur as a result;
- whether there is anything you would want to see done before the data are made available to this organisation.

Each group of 3 present your points to the other. Consider if you can make suggestions to strengthen each position.

Discuss how best to present this material to the rest of the group, including who will role play advocating for each position.

Group B: NHS clinicians and administrators doing approved research into whether doctors are prescribing medicines appropriately

Introduction

The jury's charge is about creating new records for purposes other than direct patient care. Question 2 is about who should be allowed to access and extract data from the patient records created, and for what purposes. It lists seven potential uses and users, and the jury has to decide which of these should be allowed. In each case, the potential user wants to access individual-level data (not totals) with identifiers removed. The data is anonymised (not "personal data" in the eyes of the law) but there is still a very small risk that someone could be identified from the data they access. People will only get access to the data if they agree to handle it securely, as required by law. The users will pay for access to the data – enough to cover the costs of providing access.

For this exercise, your small group must prepare to role-play presenting *and* challenging the case for the rest of the jury for this potential use.

3 group members identify reasons why NHS clinicians and administrators doing approved research into whether doctors are prescribing medicines appropriately - should be allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

When making the case, you may like to make some of the following points:

- You need to be able to access the data to find out whether doctors are prescribing:
 - the right drugs for the right illnesses and diseases;
 - neither too much nor too little;
 - at the right times.
- The research is important because:
 - it enables your organisation to learn about whether it is prescribing medicines to its patients safely;
 - it enables your health organisation to understand whether it is spending a large part of its budget in the right way, and what actions it needs to take in future years to address any problems identified in the way that medicines are prescribed locally
 - it provides essential data to prescribing advisers who visit doctors to discuss the doctors' prescribing practices, and whether they may need to change.
- You don't gain personally, and your organisation does not get any additional funding as a result of this use of the data, although identifying inappropriate prescribing can sometimes enable your health organisation to save money that could be better spent elsewhere.
- You will provide proper protection of the data and allow access only by the people who need it.
- Published statistics can be helpful, but they are not flexible enough here. They don't give you the necessary detail on prescribing that you need. Also, the statistics are always either about GPs or about hospitals but, unlike this new dataset, not both. Many patients, such as elderly patients with more than one health problem, visit and receive prescriptions from both hospitals and GPs, and it's important to investigate whether there is any inappropriate prescribing e.g. where a medicine is given to treat one condition but should not be given in conjunction with another medicine being given for another condition.

Try to think of other good reasons for you to access the data. Prepare for the challenging questions you are likely to be asked.

3 group members identify reasons to be *skeptical* of NHS clinicians and administrators doing approved research into whether doctors are prescribing medicines appropriately being allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

Possible challenges might include:

- How would this benefit ordinary citizens and patients?
- What do you and your organisation stand to gain from access to the data?
- Why should patients trust you with patient data?
- Why don't you use other available data, such as statistics published nationally, which give a breakdown of different services provided in different local areas?
- Why do *you* need to do this – couldn't it be done by someone else e.g. within the NHS?

You might also think about:

- how much risk there is of this organisation not protecting the data appropriately, and the potential harms or unfairness that could occur as a result;
- whether there is anything you would want to see done before the data are made available to this organisation.

Each group of 3 present your points to the other. Consider if you can make suggestions to strengthen each position.

Discuss how best to present this material to the rest of the group, including who will role play advocating for each position.

Group C: university staff doing approved research into whether doctors are prescribing medicines appropriately

Introduction

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For this exercise, your small group must prepare to role-play presenting *and* challenging the case for the rest of the jury for this potential use.

3 group members identify reasons why university staff doing approved research into whether doctors are prescribing medicines appropriately - should be allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

When making the case, you may like to make some of the following points:

- You need to be able to access the data to find out whether doctors are prescribing:
 - the right drugs for the right illnesses and diseases;
 - neither too much nor too little;
 - at the right times.
- The research is important because:
 - it enables you to publish evidence from which health organisations and doctors across England can learn whether they are prescribing medicines safely;
 - it enables health organisations to:
 - understand whether it is spending a large part of its budget in the right way, and what actions it needs to take in future years to address any problems identified in the way that medicines are prescribed locally;
 - provide essential data to prescribing advisers who visit doctors to discuss the doctors' prescribing practices, and whether they may need to change.
- The research is funded by a large health charity.
- You don't gain financially, but you do plan to publish papers in academic journals as a result of the research, which is an important part of developing your academic career.
- You will provide proper protection of the data and allow access only by people who need it.
- Published statistics can be helpful, but they are not flexible enough here. They don't give you the necessary detail on prescribing that you need. Also, the statistics are always either about GPs or about hospitals but, unlike this new dataset, not both. Many patients, such as elderly patients with more than one health problem, visit and receive prescriptions from both hospitals and GPs, and it's important to investigate whether there is any inappropriate prescribing e.g. where a medicine is given to treat one condition but should not be given in conjunction with another medicine being given for another condition.

Try to think of other good reasons for you to access the data. Prepare for the challenging questions you are likely to be asked.

3 group members identify reasons to be *skeptical* of university staff doing approved research into whether doctors are prescribing medicines appropriately being allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

Possible challenges might include:

- How would this benefit ordinary citizens and patients?
- What do you and your organisation stand to gain from access to the data?
- Why should patients trust you with patient data?
- Why don't you use other available data, such as statistics published nationally, which give a breakdown of different services provided in different local areas?
- Why do *you* need to do this – couldn't it be done by someone else e.g. within the NHS?

You might also think about:

- how much risk there is of this organisation not protecting the data appropriately, and the potential harms or unfairness that could occur as a result;
- whether there is anything you would want to see done before the data are made available to this organisation.

Each group of 3 present your points to the other. Consider if you can make suggestions to strengthen each position.

Discuss how best to present this material to the rest of the group, including who will role play advocating for each position.

Group D: staff employed by a local authority planning the future need for residential care homes

Introduction

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For this exercise, your small group must prepare to role-play presenting *and* challenging the case for the rest of the jury for this potential use.

3 group members identify reasons why staff employed by a local authority planning the future need for residential care homes - should be allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

When making the case, you may like to make some of the following points:

- You need to be able to access the data to find out:
 - how many older people who live in the local authority are receiving health services which suggest that they are likely to need to move to a residential care home (such as physiotherapy after a fall), and whether these health services are increasing or reducing annually;
 - how many older patients have been delayed before being discharged from hospital because there was no available bed in a residential care home, and whether delays are increasing or reducing annually.
- The research is important because the local authority has to consider whether the provision of residential care in the local area currently is sufficient, and plan for future residential care to meet expected needs of local people in future (which may mean opening or closing care homes)
- You don't gain personally, and your organisation does not get any additional funding as a result of this use of the data.
- You will provide proper protection of the data and allow access only by people who need it.
- Published statistics can be helpful, but they are not flexible enough here. They don't give you the necessary detailed information you need, and the data are always broken down by health authority, and never by local authority. Also, the statistics are always either about GPs or about hospitals but, unlike this new dataset, not both. Relevant information, such as that on falls, is held in both the GP and hospital records.

Try to think of other good reasons for you to access the data. Prepare for the challenging questions you are likely to be asked.

3 group members identify reasons to be *skeptical* of staff employed by a local authority planning the future need for residential care homes being allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

Possible challenges might include:

- How would this benefit ordinary citizens and patients?
- What do you and your organisation stand to gain from access to the data?
- Why should patients trust you with patient data?
- Why don't you use other available data, such as statistics published nationally, which give a breakdown of different services provided in different local areas?
- Why do *you* need to do this – couldn't it be done by someone else e.g. within the NHS?

You might also think about:

- how much risk there is of this organisation not protecting the data appropriately, and the potential harms or unfairness that could occur as a result;
- whether there is anything you would want to see done before the data are made available to this organisation.

Each group of 3 present your points to the other. Consider if you can make suggestions to strengthen each position.

Discuss how best to present this material to the rest of the group, including who will role play advocating for each position.

Group E: staff employed by a private company being paid by a hospital NHS trust to compare the number of people dying after surgery with other hospitals

Introduction

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For this exercise, your small group must prepare to role-play presenting *and* challenging the case for the rest of the jury for this potential use.

3 group members identify reasons why staff employed by a private company being paid by a hospital NHS trust to compare the number of people dying after surgery with other hospitals - should be allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

When making the case, you may like to make some of the following points:

- You need to be able to access the data to:
 - compare treatments and services the hospital trust has provided with other hospitals
 - compare the outcomes and specifically the number of people dying soon after surgery, for all of the different types of surgery, with figures from other hospital trusts in England;
 - check that the patients receiving surgery at the hospital are comparable to those in other hospitals in England (for example, the hospital's patients do not have more or fewer complications than average).
- This work is important so that the hospital is aware of any surgical teams within the hospital with outcomes that may mean they are putting patients at risk (for example, because of poor or outdated surgical practice)
- Hospital staff themselves could carry out this analysis but it is common practice for hospitals to contract with companies like yours because:
 - they may not be able to attract staff with the specialist skills required;
 - they may not have the sophisticated software and systems necessary to carry out this kind of analysis.
- You don't gain personally from this work, but your organisation is paid by the hospital for the work it does and that work relies on gaining access to the data.
- You will provide proper protection of the data and allow access only by people who need it.
- Statistics can be helpful, but they are not flexible enough. They don't let you carry out the details analysis of hospital deaths after surgery described above. Also, the statistics are always either about GPs or about hospitals but, unlike this new dataset, not both. You need access to GP data as well as hospital data to identify how healthy the patients are who are receiving surgery compared to that in other hospitals.

Try to think of other good reasons for you to access the data. Prepare for the challenging questions you are likely to be asked.

3 group members identify reasons to be *skeptical* of staff employed by a private company being paid by a hospital NHS trust to compare the number of people dying after surgery with other hospitals being allowed access to the patient data. Prepare a summary of your main points on one flip chart page. Prepare a summary of your main points on one flip chart page.

Possible challenges might include:

- How would this benefit ordinary citizens and patients?
- What do you and your organisation stand to gain from access to the data?
- Why should patients trust you with patient data?
- Why don't you use other available data, such as statistics published nationally, which give a breakdown of different services provided in different local areas?
- Why do *you* need to do this – couldn't it be done by someone else e.g. within the NHS?

You might also think about:

- how much risk there is of this organisation not protecting the data appropriately, and the potential harms or unfairness that could occur as a result;
- whether there is anything you would want to see done before the data are made available to this organisation.

Each group of 3 present your points to the other. Consider if you can make suggestions to strengthen each position.

Discuss how best to present this material to the rest of the group, including who will role play advocating for each position.

Group F: staff employed by an insurance company aiming to set health insurance premiums accurately

Introduction

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For this exercise, your small group must prepare to role-play presenting *and* challenging the case for the rest of the jury for this potential use.

3 group members identify reasons why staff employed by an insurance company aiming to set health insurance premiums accurately - should be allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

When making the case, you may like to make some of the following points:

- Your company provides health, life, and travel insurance cover to thousands of people across the country, and it is important that you have the necessary data in order to understand:
 - the health risks associated with a wide range of health conditions, and how they affect a person's life expectancy, and need for health treatment;
 - treatments that people receive for the health conditions, and the cost implications of those treatments;
- You aim to set insurance cover fairly according to accurate levels of risk, and without good data from health services in England, this is not possible, and some people will be wrongly over-charged (or under-charged) for the health risk they pose;
- You seek no data that identifies a person and you do not want to use it to try to set insurance premiums for a particular individual, only for types of people (e.g. those with breast cancer);
- You don't gain personally, and your organisation does not get any additional income from using the data – it allows the organisation to provide services at fair prices to different customers.
- you will provide proper protection of the data and allow access only by the people who need it
- statistics can be helpful, but they are not flexible enough. They don't give the information described above about health risks and treatments. Also, the statistics are always either about GPs or about hospitals but, unlike this new dataset, not both. For example, if you are trying to work out how much it should cost to insure a person with diabetes, you need to know what services are provided to people with diabetes, both in hospital clinics and by GPs.

Try to think of other good reasons for you to access the data. Prepare for the challenging questions you are likely to be asked.

3 group members identify reasons to be *skeptical* of staff employed by an insurance company aiming to set health insurance premiums accurately being allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

Possible challenges might include:

- How would this benefit ordinary citizens and patients?
- What do you and your organisation stand to gain from access to the data?
- Why should patients trust you with patient data?
- Why don't you use other available data, such as statistics published nationally, which give a breakdown of different services provided in different local areas?
- Why do *you* need to do this – couldn't it be done by someone else e.g. within the NHS?

You might also think about:

- how much risk there is of this organisation not protecting the data appropriately, and the potential harms or unfairness that could occur as a result;
- whether there is anything you would want to see done before the data are made available to this organisation.

Each group of 3 present your points to the other. Consider if you can make suggestions to strengthen each position.

Discuss how best to present this material to the rest of the group, including who will role play advocating for each position.

Group G: staff employed by a pharmaceutical company investigating whether you should begin research into a new drug for a genetic disease for which there is currently no treatment

Introduction

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For this exercise, your small group must prepare to role-play presenting *and* challenging the case for the rest of the jury for this potential use.

3 group members identify reasons why staff employed by a pharmaceutical company investigating whether you should begin research into a new drug for a genetic disease for which there is currently no treatment - should be allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

When making the case, you may like to make some of the following points:

- The national support group for this disease have been lobbying pharmaceutical companies for years to develop medicines for the disease – currently there are a variety of not-very-effective treatments available and patients suffer distressing symptoms and die young.
- The company must make a profit if it is to stay in business so it is vital for the company to understand how many people have the disease, and how much benefit they get from the treatments currently available.
- There is no data currently published about this disease, or about how many people are receiving the different treatments available.
- Therefore, you are seeking access to this new patient data set so that you can discover how many people are being treated for the disease, and what treatments they are receiving from their GPs and hospitals
- Without access to both general practice and hospital data it would not be possible for the pharmaceutical company to assess the market potential of a new product, and so it would investigate the potential of a new medicine no further.
- You don't gain personally, but your organisation does seek to make a profit, although whether there are profits to be made by investing millions of pounds into research for new medicine to treat this uncommon disease is currently very uncertain
- You will provide proper protection of the data and allow access only by the people who need it.

Try to think of other good reasons for you to access the data. Prepare for the challenging questions you are likely to be asked.

3 group members identify reasons to be *skeptical* of staff employed by a pharmaceutical company investigating whether you should begin research into a new drug for a genetic disease for which there is currently no treatment being allowed access to the patient data. Prepare a summary of your main points on one flip chart page.

Possible challenges might include:

- How would this benefit ordinary citizens and patients?
- What do you and your organisation stand to gain from access to the data?
- Why should patients trust you with patient data?
- Why don't you use other available data, such as statistics published nationally, which give a breakdown of different services provided in different local areas?
- Why do *you* need to do this – couldn't it be done by someone else e.g. within the NHS?

You might also think about:

- how much risk there is of this organisation not protecting the data appropriately, and the potential harms or unfairness that could occur as a result;
- whether there is anything you would want to see done before the data are made available to this organisation.

Each group of 3 present your points to the other. Consider if you can make suggestions to strengthen each position.

Discuss how best to present this material to the rest of the group, including who will role play advocating for each position.