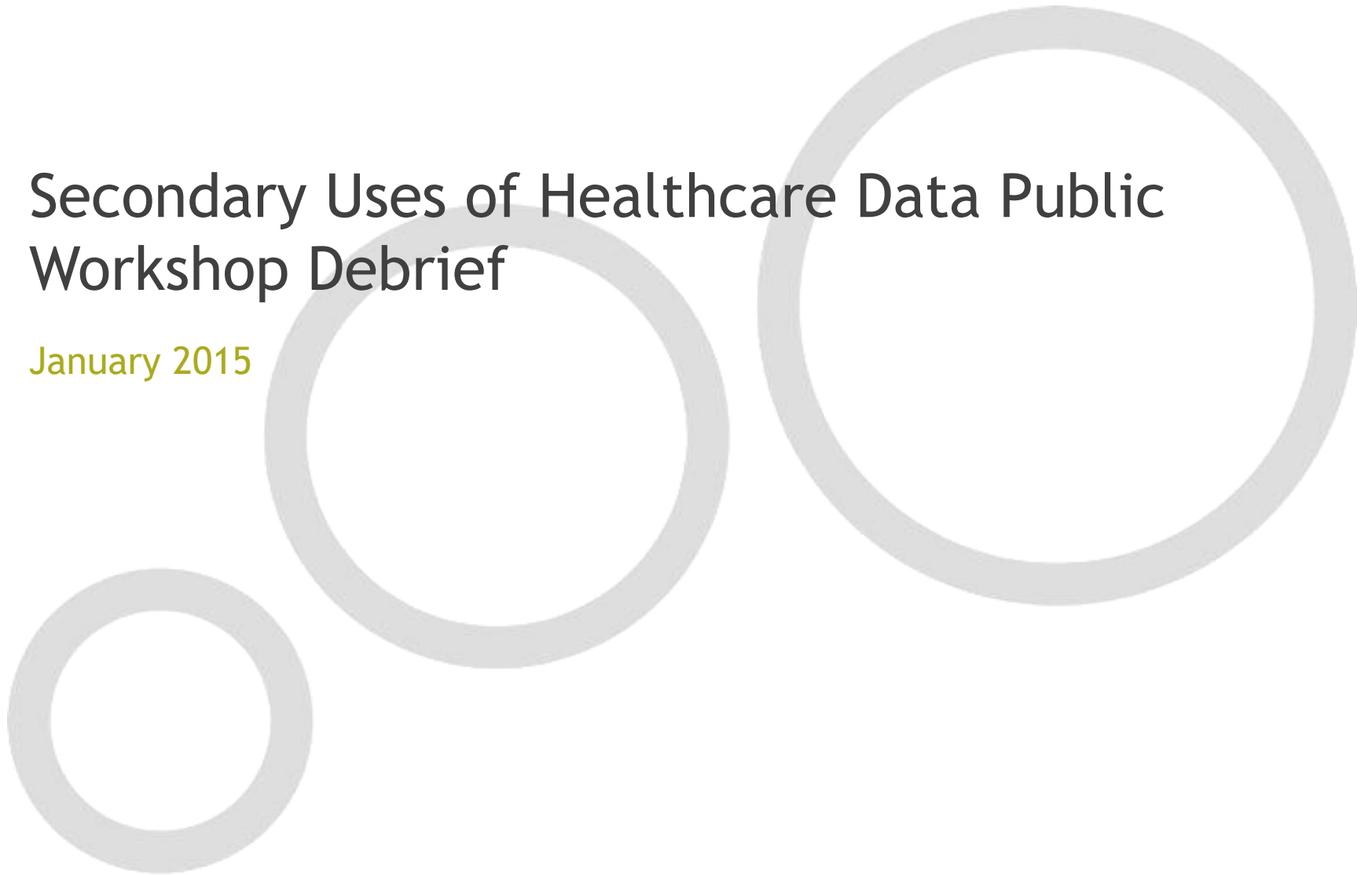


Secondary Uses of Healthcare Data Public Workshop Debrief

January 2015



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Executive summary

Executive summary

- Younger people are much more familiar with the concept of big data - and the technology that generates it - than older people
 - This means that they were much better able to imagine the benefits that secondary uses of healthcare data might bring
- All agree that healthcare data is particularly sensitive
- Despite this, secondary uses of data is not a top-of-mind issue
- There is little spontaneous understanding of how and why healthcare data might be used
- Understanding is made more difficult by the complexity of the subject, and the unfamiliarity of the language
 - For example, participants struggled to understand the difference between anonymous and pseudonymous data

Executive summary

- Participants had a range of concerns about the use of their healthcare data for secondary purposes:
 - There was a lack of confidence in the safeguards that are in place to protect data, leading to serious worries about data security
 - It was felt that there is a lack of accountability within the system
 - There were concerns about the malicious use of data by private companies
 - And in particular by pharmaceutical and insurance companies
- For some participants who came to the workshop with pre-existing concerns about privatisation, all other concerns were looked at through this lens
- However, participants were able to see benefits including:
 - Supporting research
 - Improving care
 - Improving public health
- However, acceptance of any benefits was contingent on a view of the NHS as a 'walled garden', clearly distinct from other organisations, and in particular the private sector

Executive summary

- The research identified 4 factors that influenced the level of consent that participants would ideally like to give:
 1. Clinical versus non clinical
 - A lower level of consent was felt to be necessary if the person using the data is clinically trained
 2. NHS versus non NHS
 - A lower level of consent was felt to be necessary if the data are being used within and by the NHS
 3. Medical research versus service delivery
 - Participants were willing to accept a lower level of consent for medical research than for planning/commissioning services
 4. Local versus national
 - A lower level of consent was felt to be necessary if data are being used at a local level

Executive summary

- The research also identified 6 principles around consent:
 1. The principle of ‘implied consent’ for direct care is accepted without question by all
 2. The idea of giving an overarching consent for particular types of activity is accepted as a concept and generally positively viewed as an efficient means of gaining consent
 3. Perceived sensitivity of data is the key factor to determining level of consent required
 4. The more clearly someone understands why their data is needed and how it will be used, the more likely they are to give consent
 5. The more removed a person feels from the data user, the higher the level of consent required
 6. The more someone feels they have a vested interest in the outcome of the data sharing, the lower the level of consent required



Background and methodology

Background

- The BMA is developing a Vision for the way in which patients' healthcare data is used by the NHS for secondary purposes
- The BMA held three workshops, one with the public and two with BMA members, to feed into the development of its Vision
 - This report presents the findings of the public workshop
- The workshop with the public aimed to understand:
 - Awareness and understanding of secondary uses of healthcare data and the potential benefits they can bring
 - What concerns the public have over the sharing of healthcare data for secondary purposes
 - Level of consent the public considers appropriate in different scenarios

Methodology

- On 25th November 2014 BritainThinks ran a half day workshop with 39 members of the public in BMA House, London
- Participants were recruited to ensure a spread of gender, age, family status and socio-economic background
 - 10 participants had long-term health conditions
 - 10 participants had caring responsibilities
 - 6 BME participants
- Participants were grouped at tables according to age
 - 18-25
 - 30-44
 - 45-59
 - 60+

Methodology

- The workshop was split between table discussions and information sessions:
 - Background views
 - Pub quiz
 - Presentation by Tony Calland on the current system for sharing healthcare data for secondary purposes
 - Benefits and concerns associated with sharing healthcare data for secondary purposes
 - Consent for different types of data usage
- Throughout the day participants voted on issues using individual voting pads
 - We have included data from these votes in this report. Please note that due to the small sample size, these data are only intended to be illustrative
 - A full set of the voting results can be found in the appendix



Background views

Familiarity with the concept of 'big data' varies considerably between generations

- Younger participants were entirely familiar with the concept of 'big data'
 - They were immediately able to name a range of different types of data that are generated on a regular basis, including financial data, information about use of the internet, and healthcare data
 - They were comfortable with the idea that this information about them exists
 - And familiar with much of the technology that generates it
- For older participants, this concept was much more alien
 - They struggled to identify different types of data, often referring to specific pieces of information, such as date of birth, or blood type
 - And discussions about different types of data quickly led to concerns about a loss of privacy
- These differences meant that it was much harder for older participants to understand how data might be used, and what the benefits might be

"After I registered with an NHS dentist I kept getting an advert popping up on Facebook for 'dentist'. But that was probably because I'd been searching 'dentist' on Google."

Participant, 18-29

"I think it comes from the impression we get from the media about stealing identities. It puts you on edge."

Participant, 60+

Healthcare data is seen as especially sensitive; but there is little awareness of a debate about its uses

- After discussion, there was a consensus that healthcare data, along with financial data, is much more sensitive than other types of information
 - Because of the impact that information about these things can have on how individuals are perceived
- However, secondary uses of healthcare data is not a top-of-mind issue
 - There is some awareness of a debate in the media about it - but this awareness is vague and unspecific
 - There is little familiarity with the issues around Care.data

“People who have AIDS for example would be nervous about being tested in case that information got shared.”

Participant, 60+

“I’ve never really thought about it. I guess I thought they just kept it for your records.”

Participant, 30-44

24 out of 35 participants said they were either ‘vaguely aware’ or ‘not at all aware’ of a debate about how healthcare data is used

There is little spontaneous understanding of how and why healthcare data might be used

- Participants knew very little about how their healthcare data might be used
- And many struggled to spontaneously identify any secondary uses of healthcare data
 - Most were aware of the use of data in research - but little else
 - Younger participants found it easier to imagine uses of data than older participants

26 out of 36 participants said they knew 'not very much' or 'nothing at all' about how the NHS uses information patients provide to their doctors

"If a doctor was working on a particular illness they could look at how to do it better."

Participant, 45-59

"I guess they need to know where to focus their time and effort. The NHS needs to know what to purchase."

Participant, 18-29

Understanding is made more difficult by the complexity of the subject

- Participants often struggled to differentiate between secondary uses of data and the use of data for direct care
- The language used is often unfamiliar - and the distinctions between ‘anonymous’, ‘pseudonymous’ and ‘identifiable’ data are unclear to many
 - Consequently, it was difficult for many participants to understand why different types of data would be needed in different situations
 - ‘Identifiable’ data is understood in a very literal way as name, address and date of birth
 - As a result, it was very hard for participants to understand why this would ever be needed

“I think it would be nice to know that information is being shared. My daughter had breast cancer and I can’t tell [you] how many times we would go to another department and they wouldn’t have her notes.”

Participant, 60+

“On anonymous data, given that so much is removed from it, how is it useful? Also who is anonymising it?”

Participant, 18-24



Benefits of and concerns about the secondary uses of healthcare data

There is little confidence in the safeguards that are in place to protect data

- There is a high level of cynicism about the ability of public services, and in particular healthcare services, to 'do' IT well
 - And a perception that poor IT systems are further undermined by the risk of human error - which makes data security a genuine risk
- Cynicism is compounded by a perceived lack of accountability within the system
- For many people, concerns focus on the use of data in the private sector
 - For some, these concerns focus specifically on the selling of data to insurance and pharmaceutical companies, who will then, it is assumed, use them in ways that are counter to patients' interests, e.g, to deny health insurance, or increase premiums
 - Both these concerns, and the less focused worries expressed by other participants are based on the view that companies only care about profits; pharmaceutical companies have a particularly toxic reputation
 - These concerns are often expressed anecdotally, e.g. ambulance chasing

"Can it really be kept safe? Huge data files have been lost before in the NHS and that's because of human error."

Participant, 30-44

"I'm worried about insurance companies getting their hands on my data without my consent."

Participant, 45-59

"Pharmaceutical companies can be big and evil. NHS pays for the drugs so why should they get the data for free?"

Participant, 18-24

For those who are concerned about privatisation, the secondary uses of healthcare data are often conflated with this higher-level concern

- For those who are most concerned about privatisation everything related to the NHS is viewed through this lens
 - For these people, any hint of private sector involvement significantly raises concern about the sharing of data within the NHS because of questions about where it will end up and what it will be used for
 - These concerns are exacerbated by a perceived ‘creeping’ privatisation that is thought to be currently underway
 - This raises questions about whether private companies will seek to change the rules about secondary uses of healthcare data for their own benefit
 - In general, these concerns are most strongly felt by older participants

“As services are privatised and data is shared will these companies try to change the rules on how it can be used?”

Participant, 60+

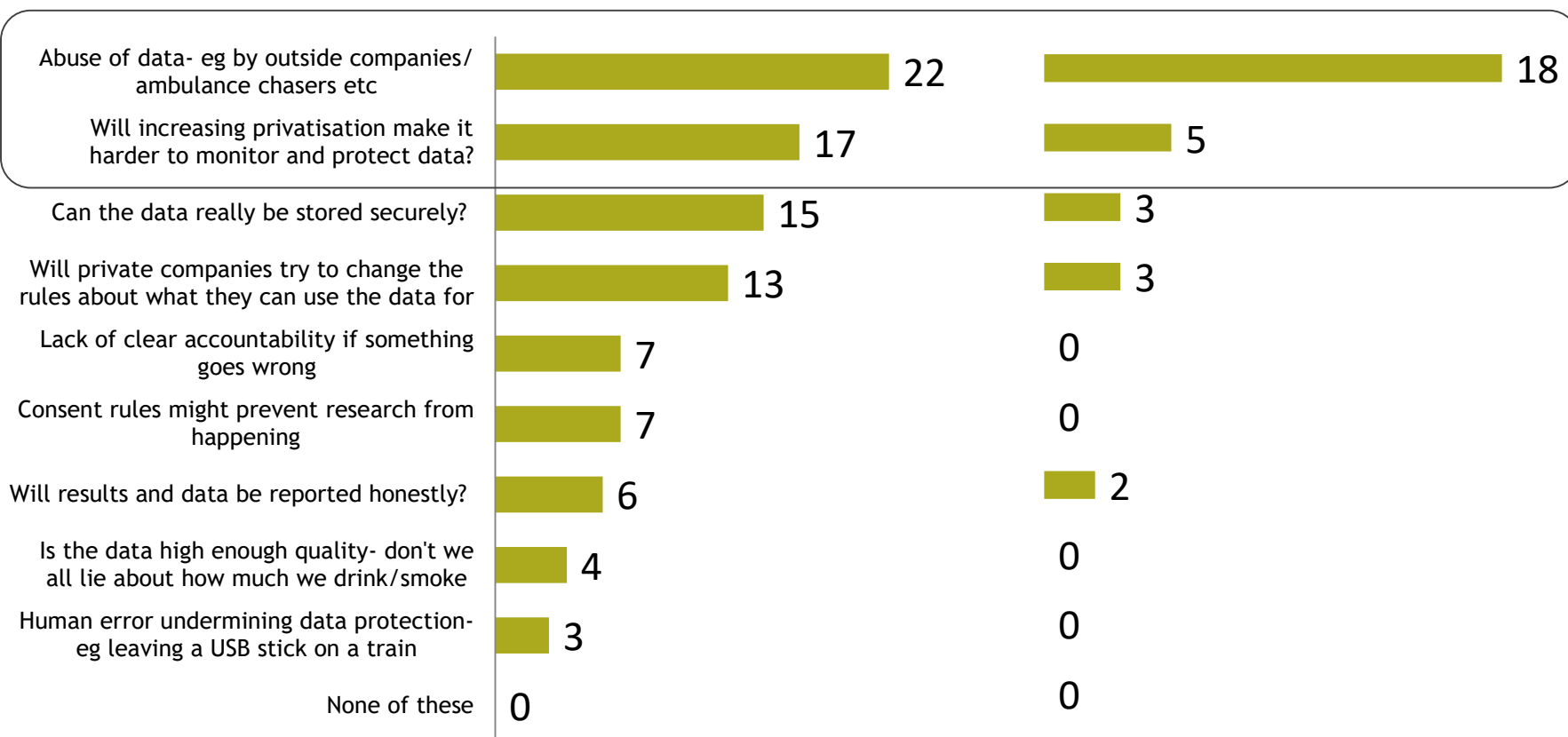
“Some of us are extremely concerned about the privatisation program which is apparently advancing. Private companies will be chasing the bottom line.”

Participant, 45-59

These concerns were reflected in the voting where the abuse of data and privatisation emerged as the two biggest concerns

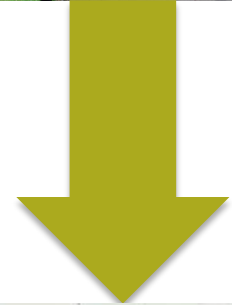
Please select the **three most important** concerns about sharing healthcare data for secondary uses

And what do you think is the **single most important** concern?



Despite concerns, there is acknowledgement of the benefits of sharing data

- The public accept the need for data sharing within the NHS
 - And they presume that it happens - particularly for the provision of direct care
- However, this acceptance is contingent on a simplistic view of the NHS as a 'walled garden', clearly separate from other organisations and institutions
 - Concern is greatest where data may be shared in a way that involves private companies
 - But even sharing with other governmental or educational institutions 'outside of the NHS' tends to increase concern



Supporting research, improving care and improving public health were the most widely accepted benefits of data sharing

- After discussion, it became apparent that those benefits that are familiar to the public, for example through the media, and which are easiest for them to understand are those that are most likely to be accepted, for example:
 - Research and the development of new medicines
 - Improving standards of care within the NHS
 - Public health
- Where benefits are unfamiliar, or it was difficult to see how they would arise from sharing healthcare data, the public were much less willing to accept them, for example:
 - Commissioning
 - Service design

“Some years ago I was offered a research thing and told it would be ‘first class treatment’ so I think that’s good.”

Participant, 60+

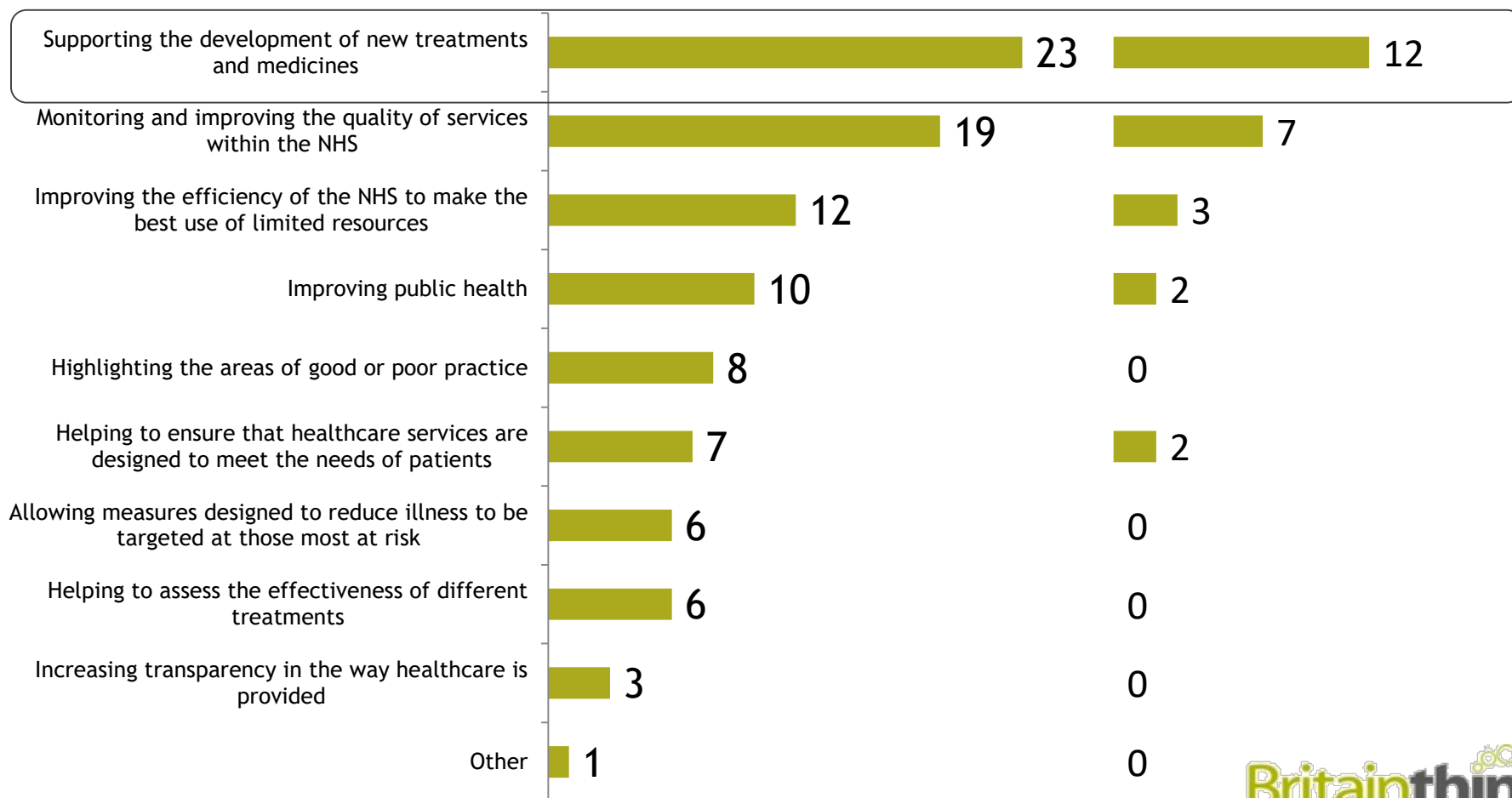
“I don’t understand if you’re not a medical doctor, what the hell are you doing hanging around a medical research project.”

Participant, 45-59

The voting shows that supporting the development of new treatments is by far the most popular benefit

Please select the three most important potential benefits of sharing healthcare data for secondary uses

And what do you think is the single most important benefit?





Levels of consent

An exercise was used to understand attitudes towards the level of consent needed in a range of scenarios

- Participants considered 4 scenarios in which healthcare data was needed for secondary uses
- Each scenario contained 2 characters who needed access to data
 - Within the scenarios, these characters either worked for different organisations, or needed different types of data
- Participants were asked to vote on which of the four levels of consent shown below they would ideally like to give each character
 - The scenarios and responses to each one can be found in the appendix

Consent implied as part of consenting to NHS treatment- no additional consent required

One-off overarching consent for the use of my data for this type of activity

Explicit consent for each such use of my data

Not happy with my data being used for this purpose

The issue of consent

There were 4 factors that influenced the level of consent participants were willing to give in each scenario

- **Clinical vs non clinical:** Where data is being used by trained clinicians a lower level of consent is seen as more acceptable compared to when it is being used by those who are not medically trained
- **NHS vs non NHS:** Where data is being used by and within the NHS a lower level of consent is seen as more acceptable than when data is being used by private companies, research organisations or (for some) charities
- **Medical research vs service delivery:** Data sharing for medical research tended to require a lower level of consent than data sharing for planning/commissioning of services purposes
- **Local vs national:** Where data is being used to address local needs a lower level of consent tended to be seen than where data is being used to address national issues

Key principles around the issue of consent

- Principle of ‘implied consent’ for direct care is accepted without question by all
 - The public expect healthcare professionals to share information
 - There was also some support for ‘implied consent’ to be more widely applied e.g. for the purpose of reviewing services or assessing the effectiveness of different treatments
- The idea of giving an overarching consent for particular types of activity is accepted as a concept and generally positively viewed as an efficient means of gaining consent
 - In practice absolute clarity would be required about what it means to give overarching consent
- Perceived sensitivity of data is the key factor to determining level of consent required
 - Very few circumstances in which participants would be willing to share data around mental health/sexual health/genetic conditions
 - If asked to do so, would want option to cherry pick which parts of their record are shared/not shared

“There’s a nurse I’ve seen a few times and I’m glad she has full access to all my records.”

Participant, 60+

“If we all gave overarching consent we could save a lot of money.”

Participant, 30-44

“I think there should be a tiered system- some data is more sensitive than others.”

Participant, 18-29

Key principles around the issue of consent

- The more clearly someone understands why their data is needed and how it will be used, the more likely they are to give consent
 - This is particularly true in cases where identifiable data or sensitive data are required
- The more removed a person feels from the data user, the higher the level of consent required
 - Participants tended to view those who had had involvement in their direct care as having the most legitimate basis for using the data for other purposes
- The more someone feels they have a vested interest in the outcome of the data sharing, the lower the level of consent required
 - Participants were more likely to require a lower level of consent where data sharing was done in order to improve treatments for a disease they hypothetically had

"I just don't understand why they need to see the identifiable information. I would need to know why."
Participant, 18-29

"The further it gets from my doctor the less happy I am about it."
Participant, 45-59

"If you've already got diabetes then anything they did in that trial would be beneficial to you."
Participant, 60+

Appendix 1: Voting scenarios

Participants were much more comfortable with their A&E data being shared than their psychiatric data

Scenario 1

Review of services using identifiable information

As part of its quality assurance programme, your local hospital is reviewing the quality of service and treatment received in its A&E Department and its Psychiatry Department.

This involves reviewing the records of the last 100 patients receiving treatment in each department. As this may also involve reviewing how quickly and effectively diagnostic tests, or other services, were provided by different parts of the hospital, identifiable records are needed.

- Sarah is a senior consultant in the A&E department and she is doing a review of the A&E department.
- John is a senior consultant in the psychiatry department and he is doing a review of the psychiatry department.

Participants to vote on level of consent for Sarah and level of consent for John

- Participants tended to select ‘implied consent’ for Sarah and ‘explicit consent for each such use of my data’ for John
 - This difference was explained by the fact that psychiatric data is seen as much more sensitive than A&E data
 - Some participants felt they would never be willing to give consent to share sensitive records
- When asked to consider how the level of consent would change if the data were being provided to a non-medical senior hospital manager or a public health consultant, participants said they would be less willing to give consent
 - In both cases participants found it more difficult to understand why that person would need to see their identifiable record
 - Non-medical staff are perceived to be outside the bounds of the patient-doctor relationship, and not, therefore, bound by the same code of ethics as medical staff
 - Because of their non-clinical role, a minority also had concerns about whether they would be motivated by patient interests to the same degree as doctors

Participants were more comfortable sharing data when it was perceived to stay ‘within’ the NHS

Scenario 2 Use of pseudonymised records for research

Sally and Tom are both doctors who have worked for many years as specialists in diabetes care within the NHS. Both have received funding from the NHS to conduct research comparing two types of treatment that are commonly used for adult-onset diabetes. They each plan to review information from the GP and hospital records of 1,000 patients who have had treatment at the local diabetic clinic over the last 3 years. The review requires the use of pseudonymised data. This means that information that would identify the patient has been replaced by a code, so that Sally and Tom cannot identify individual patients. However, the code means that information received from the general practitioner can still be linked with hospital records.

- Sally is still employed by the NHS and runs a diabetic clinic as well as conducting her own research
- Tom no longer works in the NHS but is still a registered doctor and sees patients as part of his research role

Participants to vote on level of consent for Sally and level of consent for Tom

- Participants tended to select ‘one off overarching consent’ for Sally and ‘explicit consent for each such use of my data’ for Tom
 - Because Tom no longer works in the NHS, there were questions about whether he had links to private companies, and what his motivations are
- When asked about what difference it would make if the research were funded by non-governmental bodies, participants became less comfortable sharing data
 - For many participants the involvement of a pharmaceutical company means they are no longer willing to give consent at all
 - For some even the involvement of DiabetesUK made them less comfortable as this was seen to be a less legitimate source of research funding than the NHS

Participants were more willing to share data when they felt they were directly affected

Scenario 3

Providing contact details for participation in research

Anya and Dinesh are GPs in a health centre close to the practice you are registered with. They are running a research project assessing the impact of a regime of prescribed and supervised exercise on those with asthma compared with healthy volunteers over a 12 week period. They need to recruit 100 patients who are currently receiving treatment for asthma and 100 healthy volunteers. Participants will be given a thorough health assessment and asked to answer a quality of life questionnaire at the beginning of the study and again after the 12 weeks. During the 12 weeks participants will attend a Local Authority funded leisure centre where they will be given a personalised exercise routine to be performed, with supervision, at least once a week.

Your GP has been asked to provide Anya and Dinesh with the name and contact details of patients who may be willing to participate in the study so that the researchers can invite them.

- Anya is responsible for recruiting the patients with asthma - you have asthma
- Dinesh is recruiting the healthy volunteers - you do not have asthma

Participants to vote on level of consent for Anya and level of consent for Dinesh

- Participants tended to select ‘implied’ or ‘one off overarching consent’ for Anya and ‘explicit consent for each such use of my data’ for Dinesh
 - Where the trial offers direct benefits to the patients involved, it is assumed that they will want to take part because it is in their interest
- Asked what difference it would make if the trial were conducted by a scientific researcher instead of a doctor, participants said they would be less willing to take part, and would like a higher level of consent
 - Any trials conducted by doctors ‘within’ the NHS were much more readily accepted
 - In all scenarios participants felt their GP should be the one to approach them with information about the trial

Participants found it very difficult to understand why identifiable data would ever be needed

Scenario 4 Commissioning and planning

Rita and Seb are local doctors who specialise in the planning of health services. They have been asked by NHS England to carry out a review of diabetic care in the NHS. An estimated 80% of the NHS expenditure on diabetic care is spent treating avoidable complications of diabetes, such as kidney disease and diabetic eye disease.

Patient data from hospital records will be reviewed to assess how these complications relate to the type of care the patients received in order to establish the best form of treatment. The reviewers will also investigate which parts of the country have unusually high rates of diabetic complications. This information will inform the planning of services in local areas, and will determine which services need to be improved or redesigned.

You have received treatment for diabetes and therefore your record will be assessed.

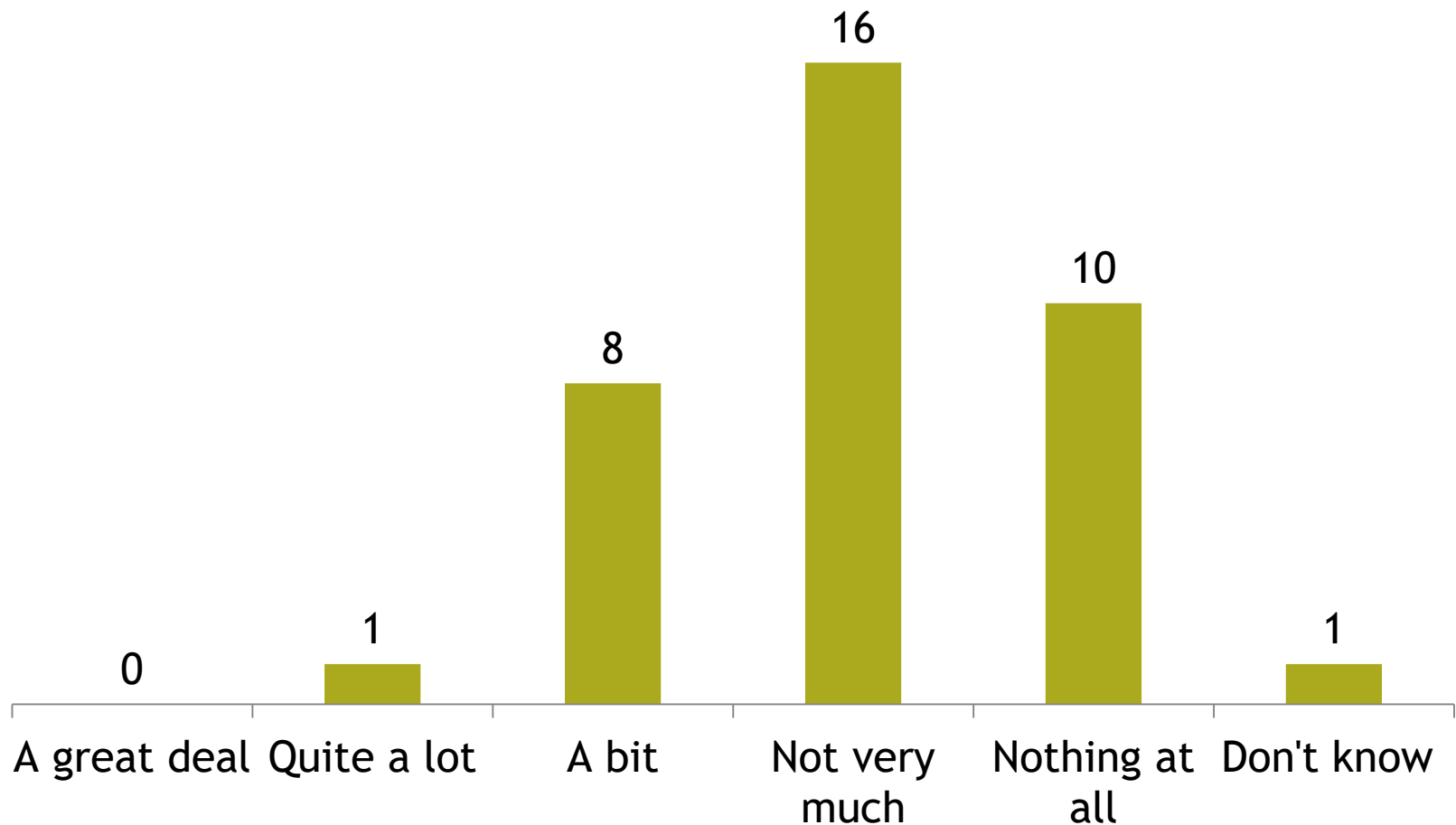
- Rita will need to see the full identifiable record for each patient.
- Seb will need anonymised data- where all identifiers have been removed - for his part of the review.

Participants to vote on level of consent for Rita and level of consent for Seb

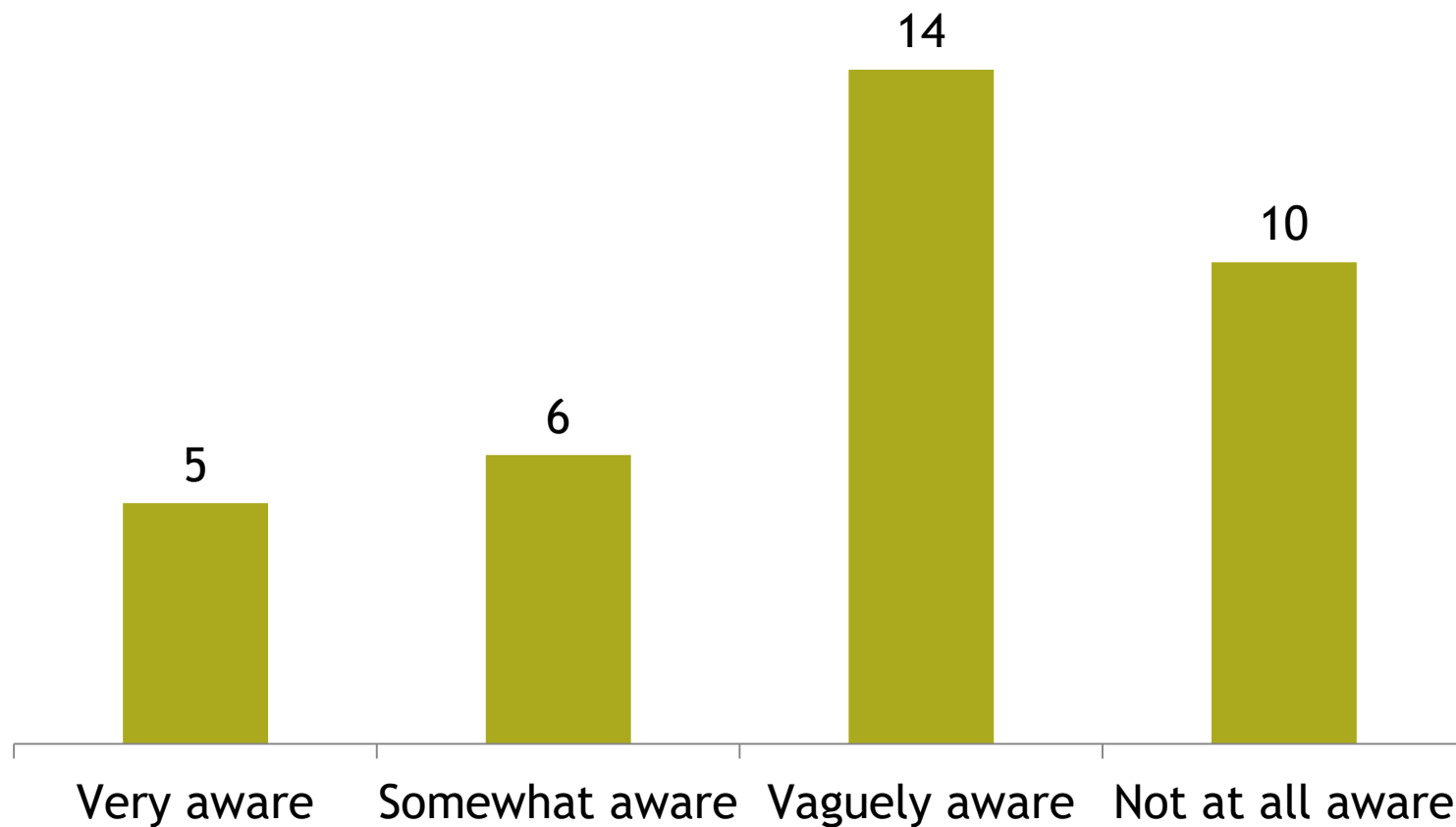
- Participants tended to select ‘one off’ or ‘explicit’ consent for Rita and ‘implied consent’ for Seb
- Asked to consider alternative data users, participants felt that where the data is anonymous, they would not require a higher level of consent
- In the case of identifiable data participants struggled to understand why non medical analysts or managers would ever need to see identifiable data
 - Where the justification for such use is less clear participants are less likely to be willing to give consent

Appendix 2: Voting results

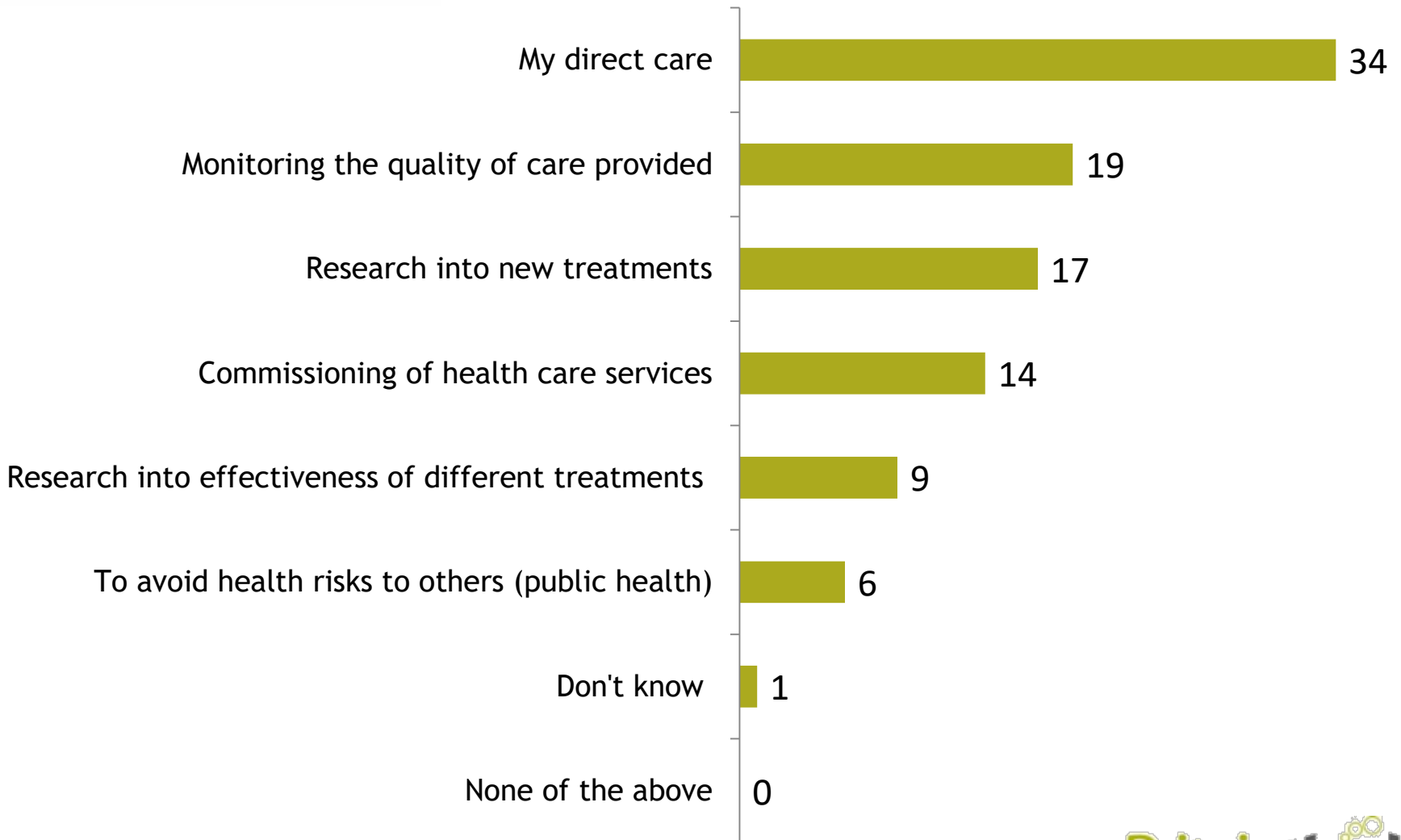
How much do you know about how the NHS uses information you provide to your doctor?



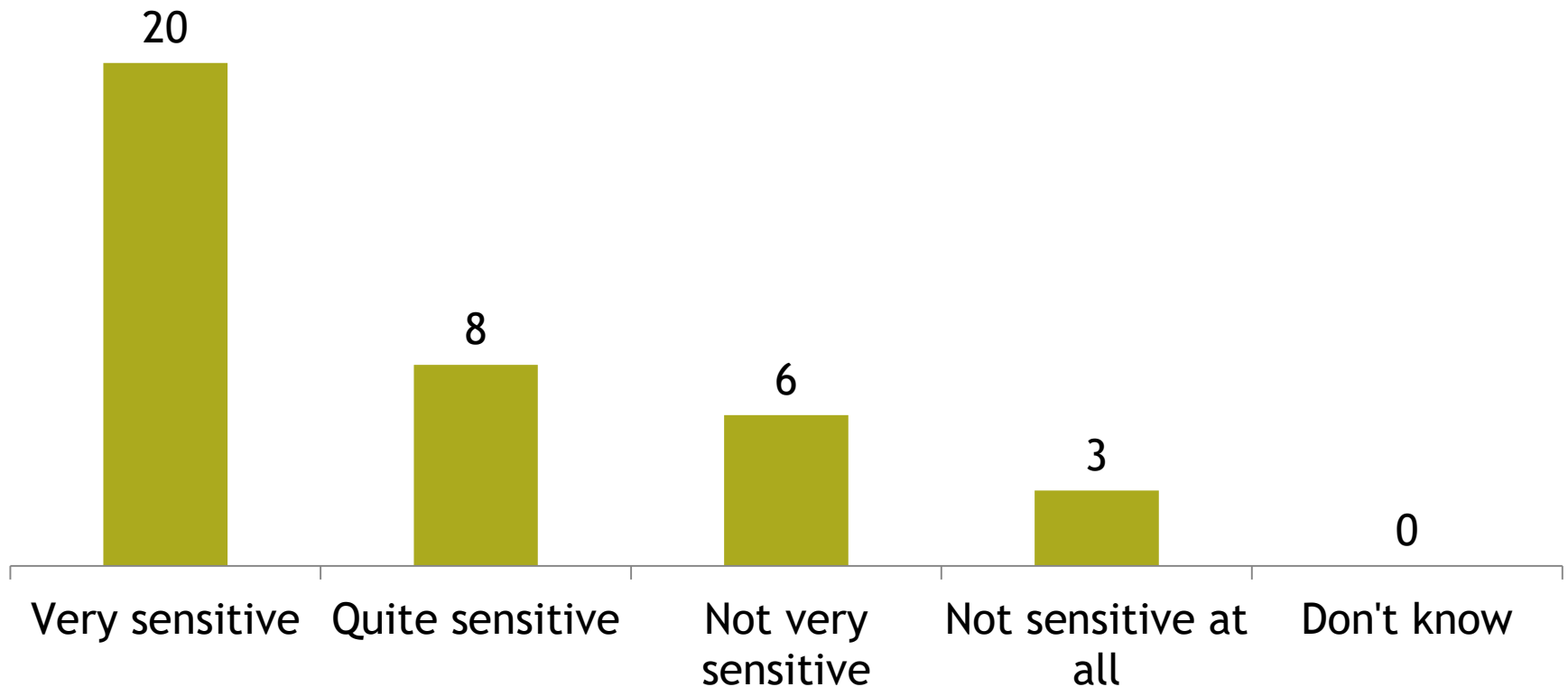
Before coming here today, how aware were you of a debate about how healthcare data is used?



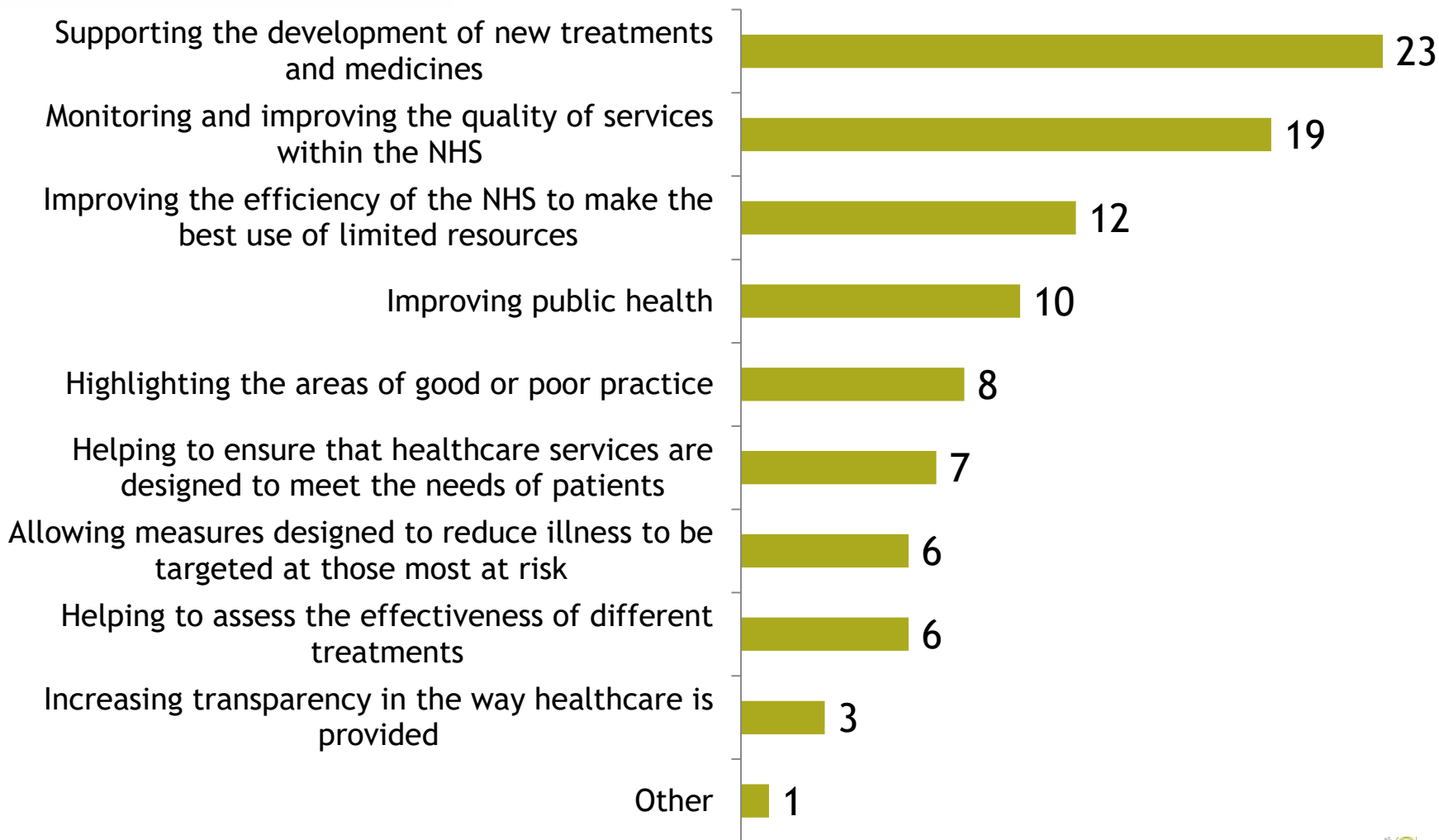
In general, what do you believe your healthcare data should be used for?



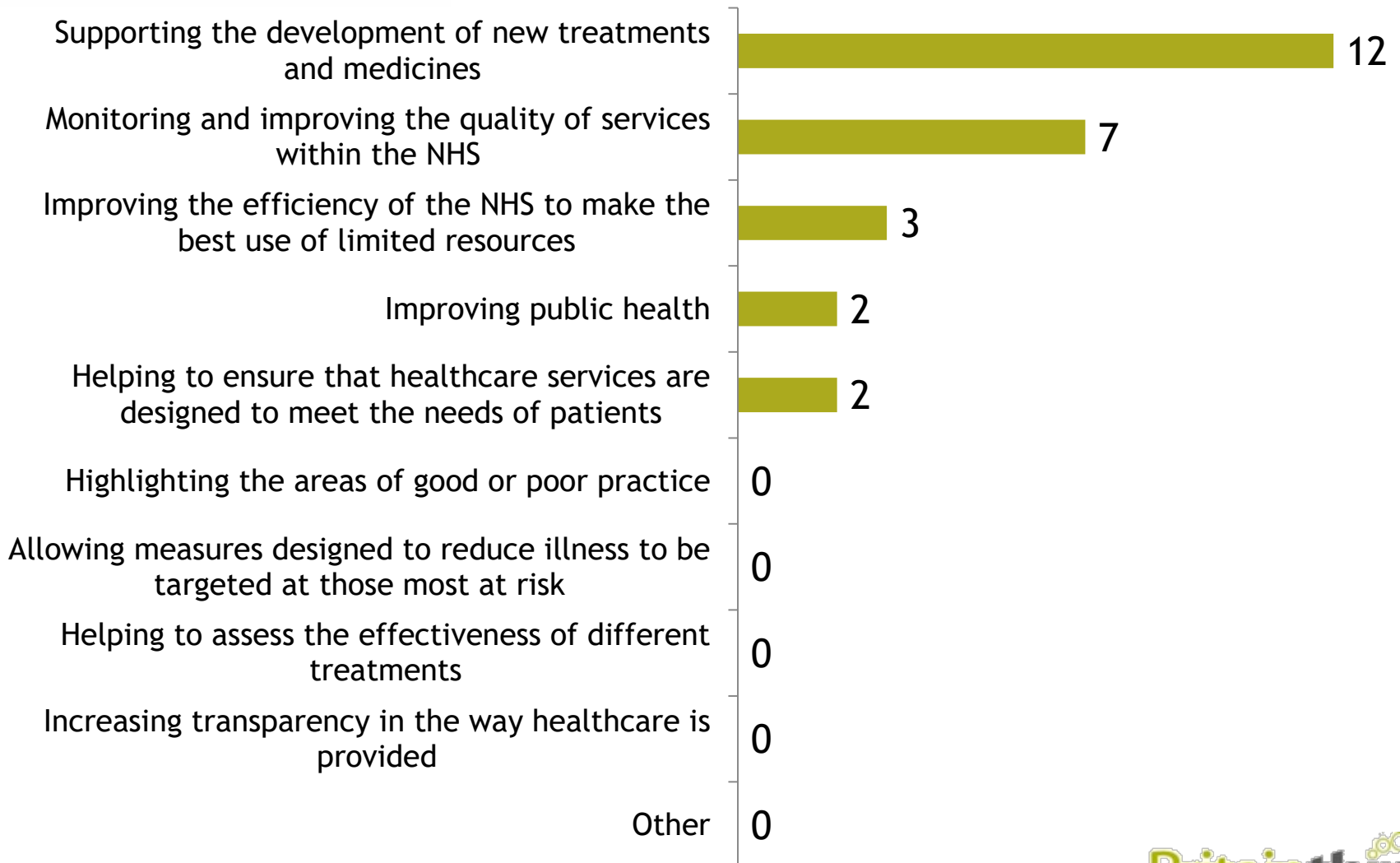
In general, how sensitive do you consider your healthcare data to be?



Please select what you think are the three most important benefits to the sharing of healthcare data for secondary uses



Please select what you think is the single greatest benefit to sharing healthcare data for secondary uses



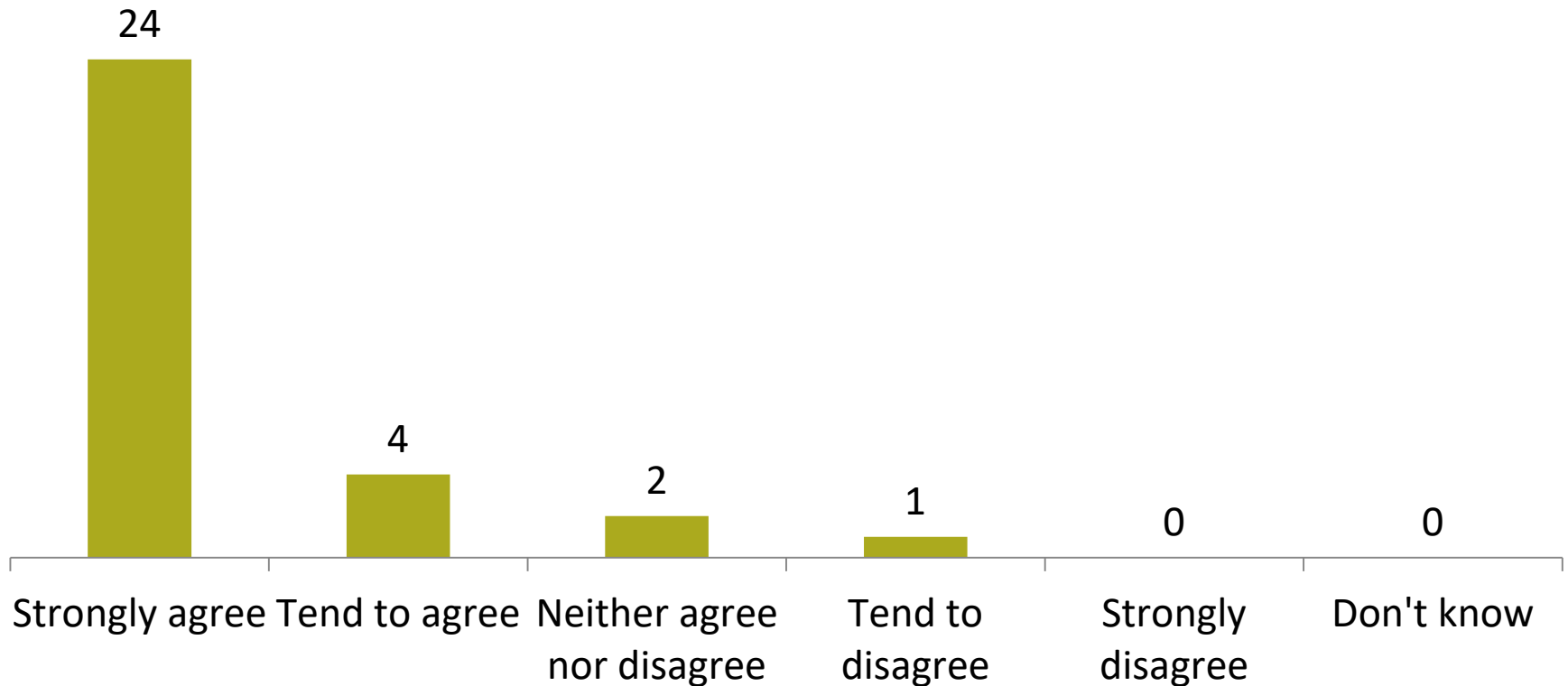
Please select what you think are the three most important concerns about sharing healthcare data for secondary uses



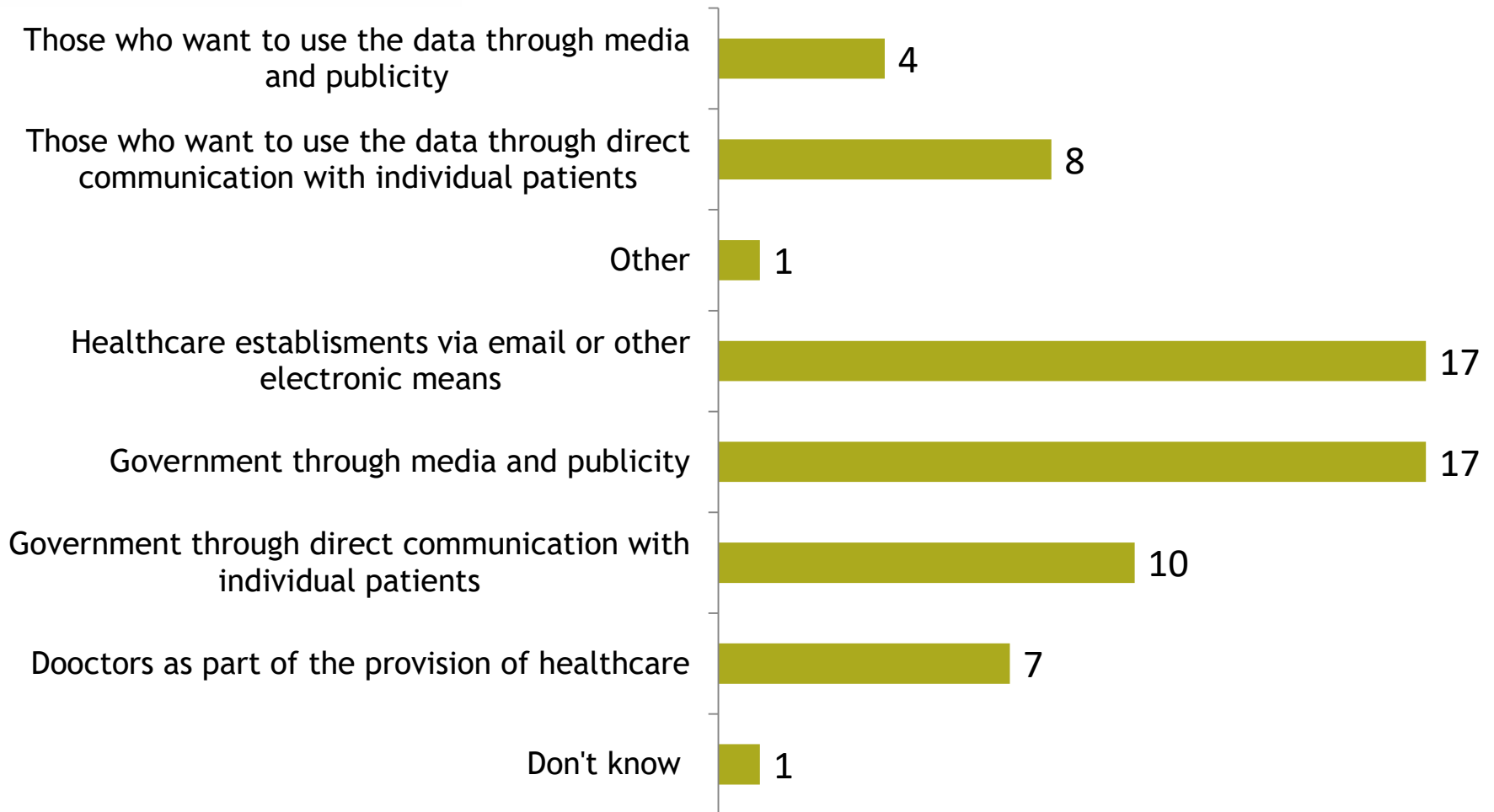
And what do you think is the single most important concern?



To what extent, if at all, do you agree with this statement: “The public should be given more information about the sharing of healthcare data for secondary uses within the NHS”



If more general information is needed about secondary uses of healthcare data, who in your opinion should provide it?



Under what circumstances, if any, would you be willing to give a one-off overarching consent to the use of your identifiable data?

