Memorandum of understanding on data-sharing between NHS Digital and the Home Office: call for evidence

PHE Publications gateway number: 2017793

Introduction

Public Health England are seeking views on the impact of data-sharing arrangements under the memorandum of understanding on the health and healthcare-seeking behaviour of migrants, specifically:

> *"What is the public health impact of the Memorandum of Understanding on data sharing between NHS Digital, the Home Office, and the Department of Health, particularly on health seeking behaviour and health outcomes of the migrant population?"*

This response, from use MY data members, looks particularly at the key points relating to this case, taken from the most recent letter between the Home Office, Department of Health and Social care and the Health Select Committee.

We used an online questionnaire emailed directly to members, and left this open for just one week. The results of that questionnaire are supplied here as evidence to Public Health England, as summary findings and as detailed response to questions.

Further details and any questions relating to this evidence submission can be directed to:

Coordinator, use MY data

coordinator@useMYdata.org.uk

Results of the use MY data members survey:
"Your views on the confidentiality of NHS data"

Background

There have been concerns that tracing immigration offenders via patient information is damaging public confidence in the use of patient data. We heard concerns about this from patients at our 12 October workshop *Commercial access to patient data* and have also received feedback from the public. Following the Health Committee's hearings and responses from NHS Digital and the Home Office, we have contacted our members to survey their views.

We opened up a short 1-week survey for use MY data members, seeking their views on some of the points raised in the letter from Caroline Nokes MP, Home Office, and Lord O'Shaughnessy, Department for Health and Social Care to the Health Select Committee.

The survey included a link to the thread of correspondence, available at http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-and-social-care-committee/news/committee-publishes-responses-on-mou-17-19/ and members were encouraged to read it.

In putting together the survey, we extracted some of the statements from the Department of Health letter, with only slight amendments to the wording for clarity. We simply asked members for their views on whether they agreed or disagreed with the statements. The survey also allowed the inclusion of additional free-text responses.

The detailed results are presented in the appendix to this short summary, both graphically and with grouped comments supplied by members.

Summary of findings

1. There was unanimous agreement amongst members (either strongly agree or agree) that patient confidentiality should be respected by ensuring that medical information about a person is properly protected.

2. Members largely agreed that sharing data was important, but that medical data should be properly protected.

3. Members felt much less certain that patients would have a reasonable expectation that data should have been shared in this instance.

4. Contrary to views stated by the Home Office and the Department for Health and Social Care, it was the strong view of members that sharing of data in the investigation of criminal offences had significant implications for public confidence.

> "As a health informatics professional and a cancer patient, I was appalled to hear that this MoU had been agreed between NHS Digital and the Ministry of Justice. I am an advocate for the use of anonymised patient data for research purposes, but this action severely undermined my own trust in HMG as a whole, and of NHS Digital in particular, as a trustee of my personal and confidential data."
>
> use MY data member

> "Once data is shared it cannot be 'unshared'."
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> use MY data member

Other points contained within the responses

The use MY data members are generally on the positive side of data usage. However, this is tempered by an overwhelming desire amongst members for there to be far greater transparency and education, which will allow patients to choose.

There was some clear overall agreement on specific points raised, with others seeing a much wider spread of opinion. To a degree this could be down to the way that the questions in the survey were phrased, but this was done deliberately to make the questions as close as possible to the statements in the letter.

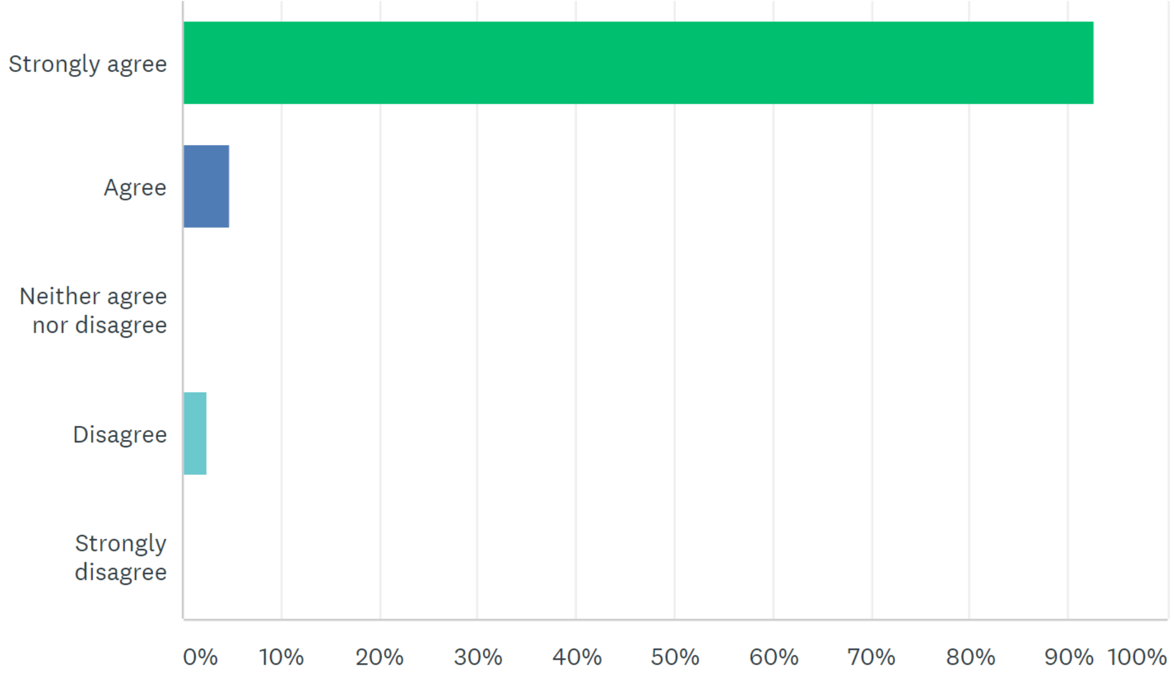
Some comments were made about the questions being poorly written. It should be noted that the question wording came, as closely as possible, from the actual letter text. This highlights the importance of clear communications, written in a lay-accessible format.

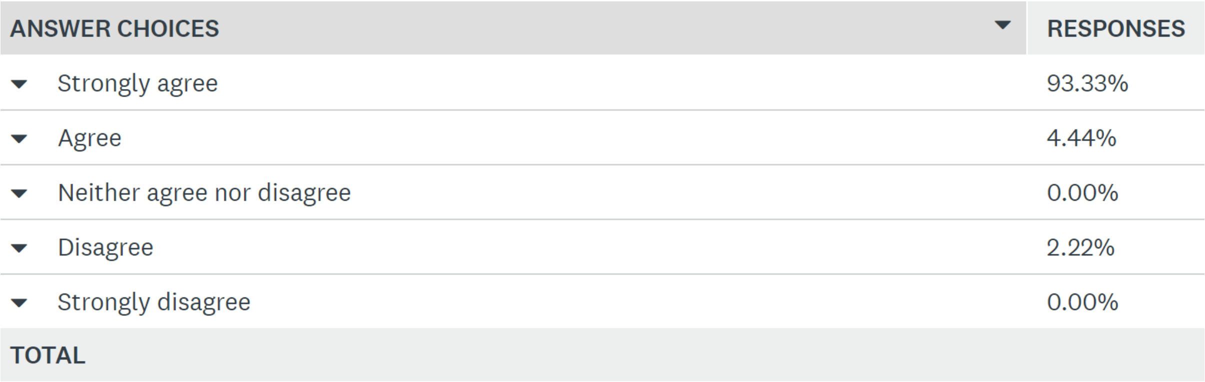
APPENDIX A: Detailed questions and responses

Question 1:

"I recognise the importance of ensuring there is a clear and robust basis for sharing personal data held by the NHS with other bodies, and agree that patient confidentiality should be respected by ensuring that medical information about a person is properly protected."

Extracted from para 3 at the bottom of page 1, http://www.parliament.uk/documents/commons-committees/Health/Correspondence/2017-19/Letter-to-Chair-of-Committee-from-Caroline-Nokes-MP-and-Lord-O'Shaughnessy-MoU-on-data-sharing-23-02-18.pdf





ANSWER CHOICES ▼	RESPONSES
▼ Strongly agree	93.33%
▼ Agree	4.44%
▼ Neither agree nor disagree	0.00%
▼ Disagree	2.22%
▼ Strongly disagree	0.00%
TOTAL	

In addition to the unanimous support for this question, individual members highlighted the following points:

“I have concerns about who the "other bodies" might be.”

“Data shared by the NHS should only be in accordance with health improvement purposes only.”

“But not to the extent that it is used against the patient's best interests or withheld when it would could improve the patient experience - always ask for permission.”

“I strongly believe that personal and confidential information given to the NHS by any individual should ONLY be used for delivering health care UNLESS a warrant has been issued signed by a member of the judiciary authorising such release.”

“I don't think that medical information can be 'properly protected' if it is to be shared with the Home Office in any form. I do not think it should be shared. I also think this question is badly phrased and difficult to understand. I hope this is not on purpose.”

“MoJ or anyone else has no right to use data collected by NHS Digital or anyone else, without permission of the data subject.”

“Should be explained to patients regarding the use of their data.”

“I feel this is paramount. However in the context of criminal intent then all avenues should be explored.”

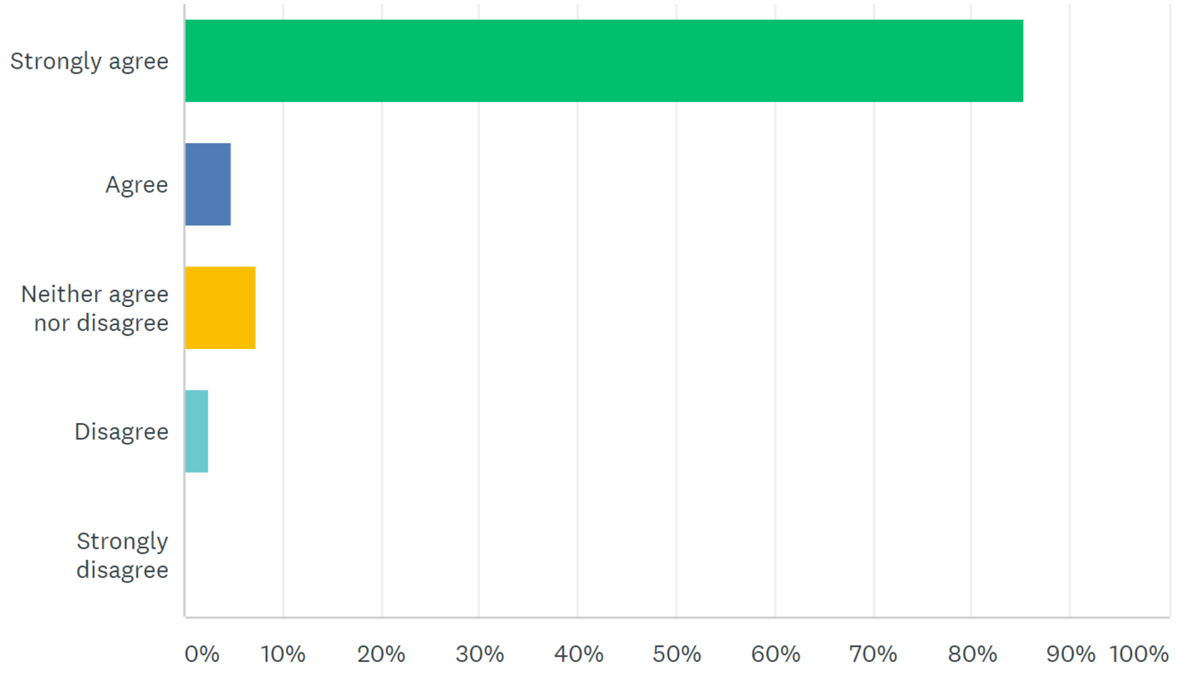
“There might be reasons for sharing data between, for instance, GPs and the DVLA when people are no longer safe to drive, or with the police for reasons of safeguarding.”

“This is vital and there must be no possibility of compromise.”

Question 2:

“The public should be given confidence in the controls which apply to the information they provide to the NHS”

Extracted from para 3 at the top of page 2, http://www.parliament.uk/documents/commons-committees/Health/Correspondence/2017-19/Letter-to-Chair-of-Committee-from-Caroline-Nokes-MP-and-Lord-O'Shaughnessy-MoU-on-data-sharing-23-02-18.pdf



ANSWER CHOICES	RESPONSES
Strongly agree	86.67%
Agree	4.44%
Neither agree nor disagree	6.67%
Disagree	2.22%
Strongly disagree	0.00%
TOTAL	

There was strong agreement (90%) on this question, although noticeably over 7% chose to neither agree nor disagree. This looks to a degree to be down to the actual question, a point highlighted in the text responses. Again, members felt that communications should be clear and lay-accessible.

Comments on this question were:

“In the light of the recent use of personal data by Facebook et al the controls should be in the hands of a statutory body.”

“And the NHS should give equally strong confidence to the patients that they will ask before releasing information.”

“As a Health Informatics Professional and a Cancer Patient, I was appalled to hear that this MoU had been agreed between NHS Digital and the Ministry of Justice. I am an advocate for the use of anonymised patient data for research purposes but this action severely undermined my own trust in HMG as a whole and of NHS Digital in particular as a trustee of my personal and confidential data.”

“Being given confidence is only valid if such confidence is well founded.”

“Once data is shared it cannot be 'unshared'. Yes, we need to have confidence in the controls - but the best control is for there to be no sharing.”

“You will not gain my confidence by allowing anybody to have my data, other than my health care providers.”

“They should feel confident about the controls to protect their information is secure.”

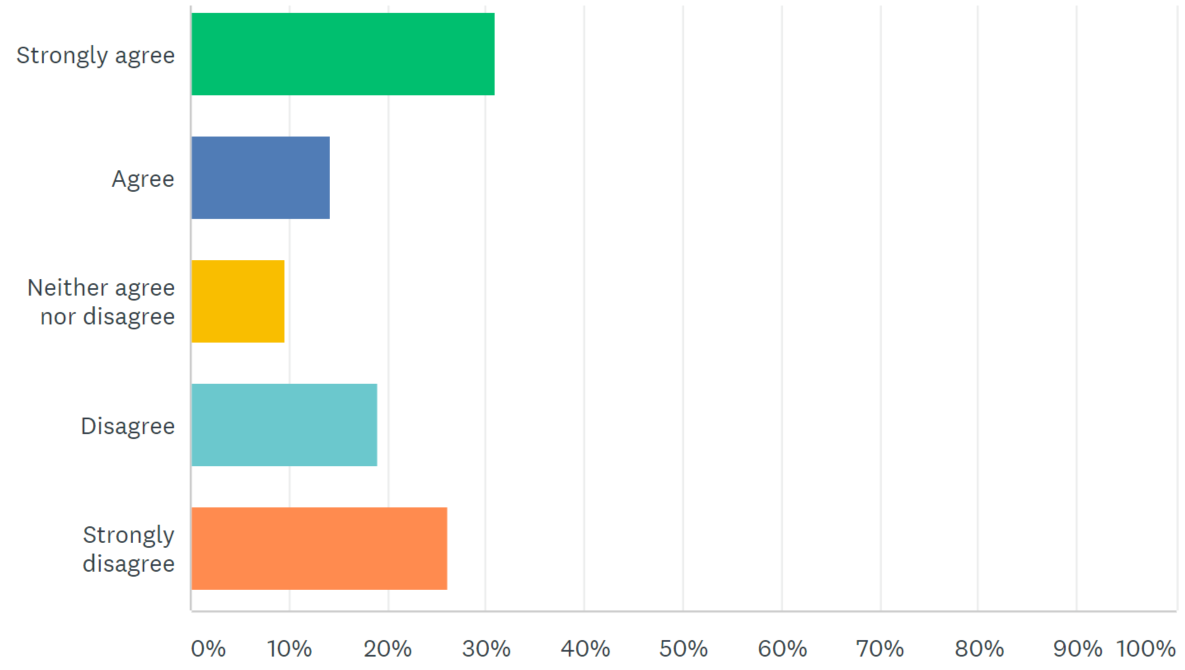
“I think this is badly worded and the question about be revised.”

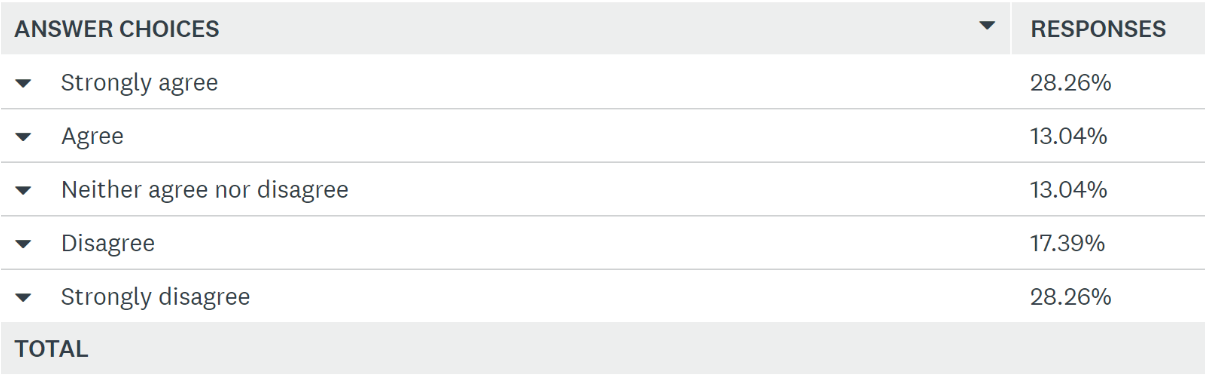
“Ordinary citizens seem particularly worried that their medical data will end up being accessed by insurance and other commercial companies once their data is no longer confidential.”

Question 3:

“A person using the NHS should have a reasonable expectation that their administrative, non-medical data (such as their names and addresses) will be shared securely between other officers within government in exercise of their lawful powers. I consider it increases public confidence that government shares data in these circumstances.”

Extracted from para 2 on page 7, http://www.parliament.uk/documents/commons-committees/Health/Correspondence/2017-19/Letter-to-Chair-of-Committee-from-Caroline-Nokes-MP-and-Lord-O'Shaughnessy-MoU-on-data-sharing-23-02-18.pdf





ANSWER CHOICES ▼	RESPONSES
▼ Strongly agree	28.26%
▼ Agree	13.04%
▼ Neither agree nor disagree	13.04%
▼ Disagree	17.39%
▼ Strongly disagree	28.26%
TOTAL	

This question clearly split the options of members, with equal numbers agreeing as disagreeing, and over 13% unable to decide.

Comments on this question were:

“My health information should not be used other than anonymised outside of health ...unless for serious prescribed purposes e.g. risk to life.”

“Would need to be very clear what these lawful powers would be.”

“Health information is specific and should not be shared without express permission especially within gov. departments.”

“In my view, such sharing of personal demographic data with authorities not directly involved in delivering my healthcare without my informed consent is at the very least immoral and at worst is unlawful. At local level a police officer needs a warrant before such data can be lawfully released by me as a Health Informatics Professional - why should someone based in Whitehall be allowed to circumvent established ethical and lawful processes? Do we really want a situation where asylum seekers or people whose visa has expired won't feel safe to ask the NHS for help? Communicable diseases need eradicating as soon as they affect individuals if we are to avoid contagion and subsequent epidemics.”

“As with any data sharing on the face of it it is a good thing, if sharing saves illegals from using the NHS then that is a positive BUT we all know once you have agreed to share you can't unshare and that shared data can then be used in other ways, I personally have zero confidence that ANY data is in fact safe you only have to look at the number of breaches there have been with national companies who are supposed to have our data kept secure to realise that if data is stored it’s at risk and as a member of the public I have to accept if I share it it will be only a % secure.”

“Failed asylum seekers by their very precarious status would not be happy with their whereabouts shared for obvious reasons.”

“I do not think data given to the NHS should be shared with other government departments in any circumstances.”

“You have no right to use any data collected about me, without my permission.”

“Only within the government and if used outside they should be informed quickly.”

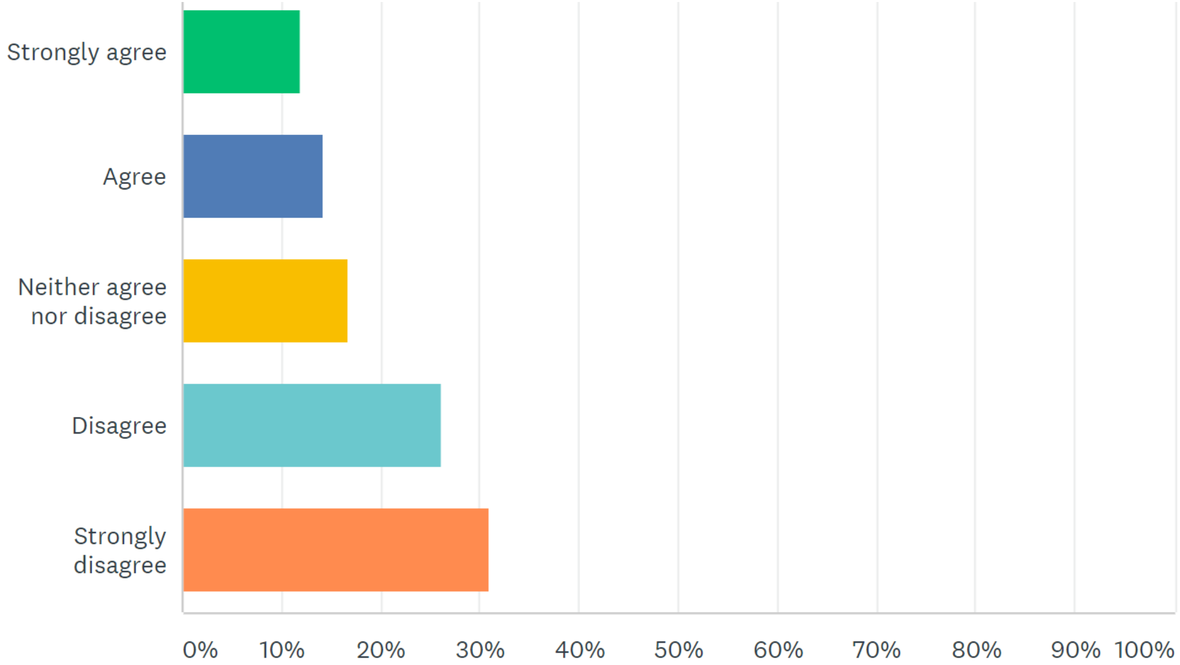
“Should it read 'other offices?'”

“That would depend on what "legal" powers the government has granted themselves. There are increasing numbers of reports about people from commonwealth countries who have lived here since childhood, but are accidentally undocumented, being hounded by the Immigration department and told to leave even though they have worked and paid taxes all their adult life.”

Question 4:

"The sharing of administrative, non-medical data (such as names and addresses) held by the NHS to enable the investigation of criminal offences has no significant implications for public confidence."

Extracted from para 2 on page 6, http://www.parliament.uk/documents/commons-committees/Health/Correspondence/2017-19/Letter-to-Chair-of-Committee-from-Caroline-Nokes-MP-and-Lord-O'Shaughnessy-MoU-on-data-sharing-23-02-18.pdf



ANSWER CHOICES	RESPONSES
Strongly agree	10.87%
Agree	13.04%
Neither agree nor disagree	15.22%
Disagree	28.26%
Strongly disagree	32.61%
TOTAL	

There was a gradation of responses to this question about sharing of administrative, non-medical data, with more towards the disagreement end of the scale. There seems to be a significant concern amongst members that this could damage public confidence in how their health data is used.

Comments on this question were:

"My health data is a private matter and it is of significant concern that criminal investigation should have a presumption of access: the opposite must apply with prescribed exceptions only meeting a high bar of necessity."

"Concerned about the inappropriate use of the data. Who would determine the level and reason for sharing data."

"After criminal charges have been brought NOT before in an investigation."

"The NHS struggles to retail public confidence. If the public believe that their data might be released for investigating unspecified "criminal offences" this confidence will be shattered. There is already evidence that legislation introduced to Prevent Terrorism is being used by local authorities to monitor the use of wheelie bins and the like - how can the public have any confidence that such loosely worded legislation won't lead to similar misuse of the law? A warrant gives this facility to the authorities, along with the assurance that a member of the judiciary has approved it, there is no need to circumvent current process - except perhaps to make life less difficult for bureaucrats who wish to circumvent the DPA and the GDPR."

"This is scare tactics and a way to convince people that sharing the data is essential to prevent crime, I think people are more aware these days that this is not the case with recent terrorists attacks highlighting that when data was shared an available it was not acted on and the attack still took place, begging the question what was the point?"

"I believe this sharing has implications for public confidence but the public interest in this sharing within the legislative framework to enforce the law and administrative rules means that it should be allowed but that necessitates clear communications to the public of what is and is not shared, the legal basis on which it is shared and the public benefits of sharing."

"It has every implication. Why wasn't this discussed in Parliament?"

"This should only happen with the consent of people involved. Given the chance to withdraw from this."

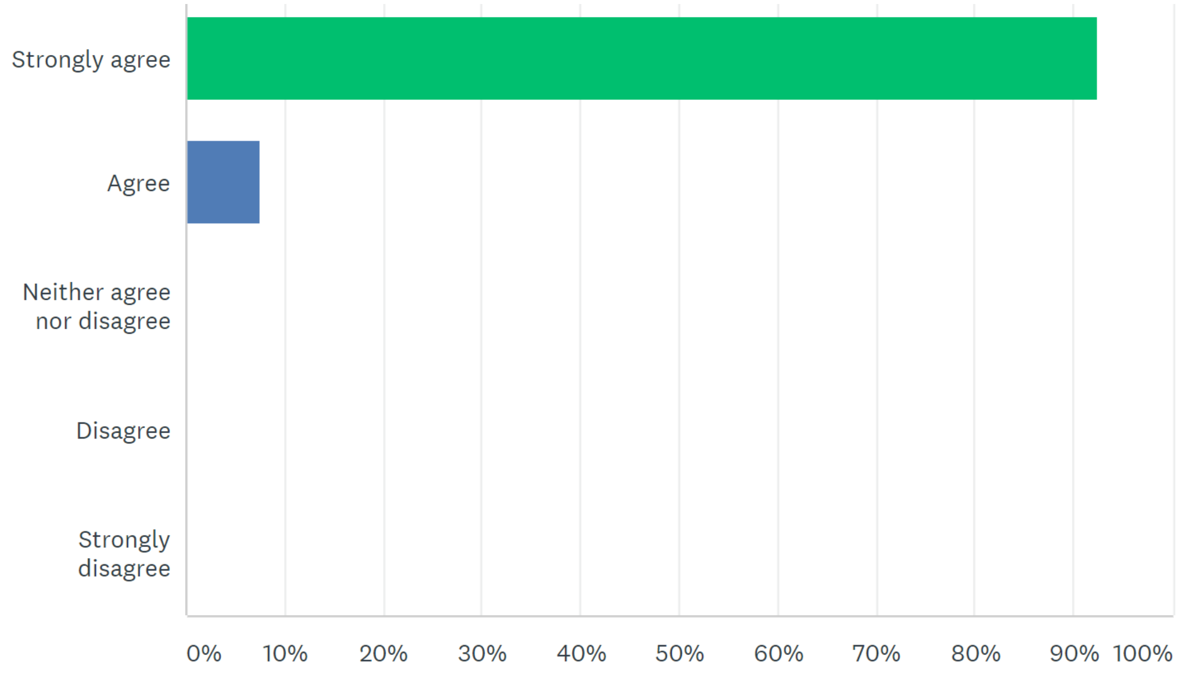
"If people are undocumented and suffering or suspect they may be suffering from dangerous diseases e.g. TB or AIDS, it is vital that they can have confidence that they will not be reported to the Immigration department and are able to get free treatment regardless, whatever the "legal" situation. Humanity comes first!"

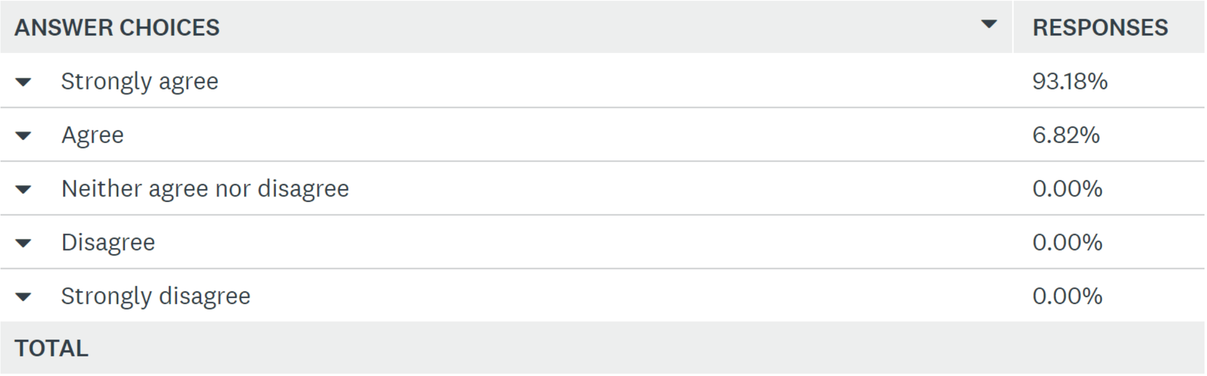
"Assuming that implications in this case would be negative? I feel that sharing this type of information in order to investigate criminal offences would increase public confidence - people share these details all the time for much less significant reasons that criminal investigations."

Question 5:

"I agree that patient confidentiality should be respected by ensuring that medical information about a person is properly protected."

Extracted from para 3 at the bottom of page 1, http://www.parliament.uk/documents/commons-committees/Health/Correspondence/2017-19/Letter-to-Chair-of-Committee-from-Caroline-Nokes-MP-and-Lord-O'Shaughnessy-MoU-on-data-sharing-23-02-18.pdf





ANSWER CHOICES	RESPONSES
Strongly agree	93.18%
Agree	6.82%
Neither agree nor disagree	0.00%
Disagree	0.00%
Strongly disagree	0.00%
TOTAL	

There was unanimous agreement, as may have been predicted, that medical information about a person is properly protected. This really just echoes what the first question was asking.

Comments on this question were:

“Properly protected is not a good question, or is only a starter question. We need concrete examples of what 'properly' means.”

“And that patients are directly involved and accountably in deciding what properly protected means.”

“There is a thin line between what is considered medical and non-medical. I strongly believe that ALL personal, confidential data held by the NHS or any organisations delivering health and social care should be "properly protected" - which the MoU fails to do. Do we really want a situation where asylum seekers or people whose visa has expired won't feel safe to ask the NHS for help? Communicable diseases need eradicating as soon as they affect individuals if we are to avoid contagion and subsequent epidemics.”

“You have not asked the question as to whether I think non-medical information derived from medical records should be shared with appropriate safeguards. I strongly agree with that question.”

“The questions in this survey are loaded. The answer to the above question is obviously yes - but the underlying implication is that non-medical information can be shared. Therefore I do not think this question should be answered in its present form.”

“All information, needs to be protected from misuse. As we know, it's not just Facebook and Cambridge Analytica who misuse our data. Governments can also. We don't want any more projects of the type Hitler started in the 30's.”

“It is part of patient confidence that this will work. Not be used for other purposes.”

“I would take this to be legal users of the NHS.”

“Particularly for the vulnerable as above.”

“There's no good purpose for sharing medical information about an individual other than for medical reasons.”

About use MY data

use MY data is a movement of patients, carers and relatives

use MY data supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

What we do

- We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.

- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.

- We provide learning resources for patient advocates on patient data issues, including:
  - hosting workshops for patients and the public, focussing on topics related to patient data
  - a library of resources of data security, consent
  - narratives from individuals about how collecting, storing and using data can help patients.

- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

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