

Health Committee
House of Commons
London
SW1A 0AA

13th April 2018

Dear Dr Wollaston MP and Health Committee members

Memorandum of understanding on data-sharing between the Home Office and NHS Digital

It has recently come to our attention that the Health Committee has an open inquiry on the above subject. I understand that National Voices has missed the previous calls for written evidence on this subject however I would like to take this opportunity to briefly outline some of our key thoughts on this matter. I hope this letter is of use to the committee.

I would also like to congratulate the committee on the work you have done so far on this inquiry highlighting the concerns surrounding the public interest test. We also have particular concerns on this aspect of the MoU and wish to explain these further.

Public interest: migrant rights and the response of a compassionate society

NHS digital has stated that requests for information received from the Home Office must show that they are in the public interest to be approved. It would appear from the evidence provided during this inquiry that, other than the minority of cases which are requested based on welfare grounds, this interest test is not on a case-by-case basis as National Voices would interpret and is instead an administrative function based on assumptions of what the general public is concerned about.

National Voices is concerned on a humanitarian level that migrants should not be abandoned by society, and in particular that they should be able to maintain their and their families' health, and access emergency care, without fear.

We believe that to fail to value migrants' health is to underestimate the large amount of the public who are compassionate to the issues surrounding migrant rights. Immigration crimes are not inherently violent and the migrants and asylum seekers being sought by the Home Office through the MoU often do not pose an immediate danger to the public; and the public is sensitive to that.

The public interest test being assessed in this particularly narrow way also negates that migrant rights exist which entitle some of those without indefinite leave to remain to have some recourse to public funds in certain situations. There does not appear to be any process for this right of migrants to access healthcare in the same way as a British citizen to be balanced against any perceived public interest.

Public interest: protection of public health

We have read the submission of Public Health England and agree with many of its key messages. We are concerned to see that the implementation of the public interest test does not take into account any balancing of the wider public interest in protecting public health, including by identifying, treating and preventing the spread of communicable disease. This may be of particular significance during times of international health emergencies such as the recent outbreaks of both the Zika and Ebola viruses.

Public interest: trust in the NHS protecting and sharing our data appropriately

As we approach the implementation date for GDPR as well as the new NHS opt-out for sharing identifiable patient information, the public is being asked more and more to trust the government and its arm's length bodies with our data. While concern for the NHS as a whole remains highⁱ, it is still a public institution that garners trust from many. Despite pressures and scandals, the majority of the public trusts both doctors and nurses to put the interests of their patients above the convenience of the hospital at least most of the timeⁱⁱ. It is therefore not surprising that every day thousands of people convey highly sensitive personal data to healthcare professionals, believing that they are doing so for their own benefit.

Figures from Understanding Patient Data suggest that more than two thirds of the public do not know how health data is used in the NHSⁱⁱⁱ. Additionally trust in hospital managers is far lower than in doctors and nurses. While there is still work to be done to build public trust with the NHS as a whole, there is also a need to maintain individual trust in an immediate clinical setting.

Contrary to what NHS Digital and the Home Office have suggested, National Voices does not believe that this memorandum of understanding (MoU) is

only a ratification of an existing process. Instead we are of the opinion that this MoU has exposed that key governmental players have failed to act in a trustworthy manner for a prolonged period of time. It has shown that when left unchecked and uncontrolled the Home Office and NHS Digital have manipulated existing 'grey areas' in data protection law, and have not acted in the best interests of the individual, and arguably not for the wider public benefit that trust in data sharing can ensure.

Further to this, in the letter written by both Lord O'Shaughnessy and Caroline Noakes MP dated 23rd February, it is stated that:

"We do not consider that a person using the NHS can have a reasonable expectation when using this taxpayer-funded service that their non-medical data, which lies at the lower end of the privacy spectrum, will not be shared securely between other officers within government in exercise of their lawful powers in cases such as these. We consider it increases public confidence that government shares data in all these circumstances."

We find this statement and attitude to be particularly concerning, as it implies that this level of personal information sharing could very quickly become the thin end of the wedge or indeed the norm. The committee has been told numerous times that NHS Digital has not provided data to other governmental departments up to this point. We are concerned that this statement above shows a potentially laissez-faire attitude from the government to both data privacy and what the public should expect from its governmental bodies. There is a strong risk that single cases of this type where the authorities are perceived not to have handled patient information in a trustworthy manner can damage the cause as a whole.

There are numerous members of the VCSE sector currently being very active in demonstrating, and promoting to the public, the benefits of data sharing for care and research purposes; particularly in the run up to the opt-out and GDPR. Our sector has taken up the challenge set by government and is working to strengthen public trust in data usage and storage. National Voices and our members want to continue to do this but when the government and authorities do not act in trustworthy ways, this undermines our effectiveness.

National Aids Trust

In the interest of transparency, please note that the National Aids Trust (NAT) is a member organisation of National Voices. As such we have spoken with Yusef Azad, Director of Strategy at NAT, about the oral evidence he gave to the committee in January.

Irrespective of NAT's membership of National Voices, National Voices would like to offer our support to the oral submission of Yusef and agreement with the points he raised.

Yours sincerely,

Hannah Chalmers
Policy and Public Affairs Lead at National Voices

ⁱ <https://www.ipsos.com/ipsos-mori/en-uk/concern-about-nhs-jumps-highest-level-2003>

ⁱⁱ <https://www.kingsfund.org.uk/blog/2015/12/public-trust-doctors-nurses>

ⁱⁱⁱ <http://understandingpatientdata.org.uk/>