



House of Commons
Health and Social Care
Committee

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

Fifth Report of Session 2017–19



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Fifth Report of Session 2017–19

*Report, together with formal minutes relating
to the report*

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Health and Social Care Committee

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Contacts

All correspondence should be addressed to the Clerk of the Health and Social Care Committee, House of Commons, London SW1A 0AA. The telephone number for general enquiries is 020 7219 6182; the Committee's email address is hscocom@parliament.uk.

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Summary

NHS Digital, the body which provides national information, data and IT services for patients, clinicians, commissioners and researchers, has entered into a memorandum of understanding (MoU) for the purpose of processing information requests from the Home Office to NHS Digital for tracing immigration offenders. The MoU was published late in 2016 and came into effect on 1 January 2017, although the practices which it now governs were being undertaken for some time before that on an ad hoc basis.

Concerns expressed about the practices enshrined in the MoU included:

- incompatibility between the disclosure of information about people in contact with health services and the obligations of confidentiality assumed to apply to that information;
- the risk that sharing of patients' addresses with other Government departments will become accepted as normal practice;
- the wider effect on public perception of the confidentiality of data supplied to the NHS; and
- the knowledge that information may be passed to immigration authorities could deter people from seeking treatment, resulting in detriment to the individuals concerned, hazard to public health, and greater cost to the NHS due to more expensive emergency treatment needing to be administered later.

Following receipt of representations from a number of organisations, both official and non-governmental, about the practice of data-sharing governed by the MoU, we took oral evidence in a single session in January 2018. On the basis of the evidence we heard then, and exchanges of correspondence published by our predecessor Health Committee in March 2017, we wrote to NHS Digital on 29 January requesting it to suspend its involvement in the MoU and undertake a further and more thorough review of the consequences and wider implications of sharing addresses with the Home Office for immigration tracing purposes.

Ministers in the Home Office and Department of Health and Social Care and NHS Digital itself responded to our letter in late February 2018, rejecting the request to suspend the MoU. Consequently we took further oral evidence in March 2018, from the Chair and Chief Executive of NHS Digital. We were looking for a very much more convincing case for the continued operation of the MoU than had been presented so far.

We regret that we did not hear such a case. Instead, we have been left with serious concerns about the ability of the Chair and Chief Executive of NHS Digital to understand, and act in accordance with, NHS Digital's role as a steward of health and social care data. The leadership of NHS Digital has not been sufficiently robust in upholding the interests of patients or in maintaining the necessary degree of independence from Government.

We also have serious concerns about Government policy on the confidentiality of data collected for the purposes of health and social care as expressed in the Ministers' response to our letter to NHS Digital.

We repeat the conclusion of our 29 January letter that NHS Digital should suspend its participation in the memorandum of understanding until the current review of the NHS Code of Confidentiality is complete. It should make a decision on whether the practice of data-sharing for immigration tracing purposes should continue in the light of the reviewed Code, after proper consultation with all interested parties, and with the full involvement of experts in medical ethics. Its decision should also take full account of the public health concerns raised by Public Health England and the outcome of PHE's review of the impact of the MoU on health-seeking behaviours.

In the meantime, the review of the NHS Code of Confidentiality should also consider and consult upon the statement of Government policy on data-sharing which was contained in the Ministers' response to our letter of 29 January, and advise Ministers on whether it is an appropriate statement of policy on the sharing of data collected and held for the purposes of health and care.

We are deeply concerned that accepting the Government's stated position would lead to sharing non-clinical data such as addresses with other Government departments. We believe that patients' addresses, collected for the purposes of health and social care, should continue to be regarded as confidential.

Background

The memorandum of understanding

1. Early in 2017 our predecessor Health Committee was contacted by the National Aids Trust and Doctors of the World, representing a number of charities and other organisations involved with the treatment of refugees and other migrants, expressing their concern about a Memorandum of Understanding (MoU) on processing information requests from the Home Office to NHS Digital for tracing immigration offenders, which was published late in 2016 and came into effect on 1 January 2017.¹
2. The MoU formalises arrangements for the Home Office to make disclosure requests to NHS Digital for the purpose of tracing immigration offenders and vulnerable people who may be at risk, and, subject to assessment of the appropriateness of the request, for NHS Digital to provide the information requested.
3. The data required and requested by the Home Office is strictly limited to demographic/administrative details covering name (or change of name), date of birth, gender, address and the date of their NHS registration. It does not include any clinical information or information relating to the health, care or treatment of the individual.²

Concerns expressed

4. The concerns expressed about the MoU covered a number of areas:
 - a perceived lack of legal basis for the disclosure of the information;
 - incompatibility between the disclosure of information about people in contact with health services and the obligations of confidentiality assumed to apply to that information;
 - the risk that sharing of patients' addresses with other Government departments will become accepted as normal practice;
 - the wider effect on public perception of the confidentiality of data supplied to the NHS; and
 - the knowledge that information may be passed to immigration authorities could deter people from seeking treatment, resulting in
 - detriment to the individuals concerned,
 - hazard to public health, and
 - greater cost to the NHS due to more expensive emergency treatment needing to be administered later.

1 <https://www.gov.uk/government/publications/information-requests-from-the-home-office-to-nhs-digital> [accessed 24.03.18]

2 [Response to question 3, Annex A to the letter from the Minister for Public Health to the Chair of the Committee, 7 March 2017.](#)

5. The organisations were also concerned at the process which had led to the publication of the MoU, arguing that they had been given commitments of meaningful consultation with them before any arrangements were finalised which they considered were not fulfilled. They further argued that the arrangements set out in the memorandum were deserving of greater Parliamentary and public scrutiny than they had received.³

Exchanges of correspondence, and request for an inquiry

6. Our predecessors responded by means of a number of exchanges of correspondence on the matter between the Chair and the Minister for Public Health, the Chair of NHS Digital, the Chief Executive of Public Health England, the Chief Executive of the General Medical Council and the National Data Guardian. The correspondence is all available on our website.⁴

7. Following the May 2017 election, the same coalition of organisations wrote to our Chair asking the Committee to continue its scrutiny of the arrangements set out in the MoU. The Chair also received a letter from the Chair of the BMA medical ethics committee requesting that the Committee hold an inquiry into the MoU.

National Back Office tracing service review report

8. On 7 November 2017, NHS Digital published the report of a National Back Office (NBO) tracing service review.⁵ The review had its origins in concerns expressed at a Health Committee hearing in February 2014 on the care.data database,⁶ one of four hearings held by our predecessors in the 2010 Parliament on the handling of NHS patient data.⁷ The NBO review started in January 2015 and concluded in 2016. It considered the arrangements by which NHS Digital responds to sanctioned tracing requests from a range of agencies and for a range of purposes. As well as Home Office immigration tracing, these purposes include tracing requests to locate individuals who have been identified as potential bone marrow donors, to aid charities supporting people wanting to re-establish contact with lost family members, and to locate individuals sought in regard to the investigation of a crime or in relation to criminal proceedings.⁸

9. The NBO review report shows that Home Office (Immigration) tracing requests account for by some distance the largest number of such requests received by NHS Digital.

Year	Total number of tracing requests	Number of those which were immigration tracing requests
2014–15	8,910	3,501 (39%)
2015–16	12,210	6,774 (55%)

Source: NBO Review report, page 18.

3 [MOU0002](#)

4 <http://www.parliament.uk/documents/commons-committees/Health/Correspondence/2016–17/Correspondence-Memorandum-Understanding-NHS-Digital-Home-Office-Department-Health-data-sharing.pdf>

5 NHS Digital, [National Back Office Tracing Service review](#), 7 November 2017 (hereafter “NBO review”).

6 Oral evidence taken on 25 February 2014, [Care.data database](#), HC (2013–14) 1105.

7 See <http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2010/cdd-2014/>

8 [NBO review](#). In the 2017 calendar year there were 6,171 immigration tracing requests ([MOU0004](#)).

It is notable that immigration tracing requests accounted for virtually all the increase in tracing requests received by NHS Digital between 2014–15 and 2015–16.

Legal basis for the disclosure of information to immigration services

10. The MoU itself sets out the legal basis for the disclosure of information from NHS Digital to the Home Office:

3.3 NHS Digital may disclose information under s.261(5) of the Health and Social Care Act 2012. Section 261(5)(e) provides a basis for disclosure where the disclosure is made in connection with the investigation of a criminal offence (whether or not in the United Kingdom); section 261(5)(d) provides a basis for disclosure where the disclosure is made in circumstances where it is necessary or expedient to have the information for the purpose of exercising its functions under or by virtue of any provision of any Act, and s.261(5)(c) provides a basis for disclosure where the disclosure is necessary or expedient for the purposes of protecting the welfare of the individual. These parts of s.261(5) are subject to the common law duty of confidentiality which is not absolute (see s.261(6)): the common law duty may be overridden in certain circumstances including where the public interest justifies disclosure.

11. The legal basis for the disclosure of information under the MoU is subject to judicial review. The grounds for the judicial review relate to the following claimant concerns:

- breach of Article 8 of the European Convention of Human Rights and Article 8 of the Charter of Fundamental Rights of the European Union;
- discrimination contrary to Article 14 (taken with Article 8 of the European Convention of Human Rights) of the European Convention of Human Rights and Article 21 of the Charter of Fundamental Rights of the European Union;
- indirect discrimination contrary to s19 of the Equality Act 2010;
- breach of the Public Sector Equality Duty;
- breach of the Data Protection Act 1998.⁹

12. In our work on the MoU, we have not sought to examine the legality, or otherwise, of the data-sharing arrangements which it sets out. That is properly for the courts. Our consideration of those arrangements has been focussed on whether they are justified in policy terms, and the ethical considerations, given the concerns which have been expressed about confidentiality and about the potential detriment to individual and public health.

⁹ Statement of Grounds in the case between Migrants Rights Network (Claimant) and the Secretary of State for the Home Department (First Defendant) and the Secretary of State for Health (Second Defendant) and NHS Digital (Interested Party), available from [Migrants Rights Network](#).

Oral evidence in January 2018, and our response

Oral evidence on 16 January

13. We took oral evidence on 16 January from representatives of three non-governmental organisations concerned with the welfare of immigrants, Public Health England, and a representative of the National Data Guardian. At the same hearing we also heard evidence from Ministers and officials in the Home Office and Department for Health and Social Care, and from the Chief Executive of NHS Digital and the senior non-executive director who concluded NHS Digital’s National Back Office review. The transcript of that session is available on our website.¹⁰

Our letter to NHS Digital

14. Following the session, on 29 January, we wrote to NHS Digital requesting that it withdraw from the MoU and stop sharing information with the Home Office for immigration tracing purposes, pending a review of its assessment of the public interest test. The full text of our letter can be found as an appendix to this report. In outline, we argued:

- the Home Office has a responsibility to seek to identify immigration offenders, to re-establish contact with them, and to take the required enforcement action, and it is understandable that it should seek from NHS Digital information which would assist it in fulfilling that responsibility;
- however, NHS Digital should not place assistance to the Home Office above the serious adverse consequences of a decision to share information with them;
- NHS Digital has not fully considered and appropriately taken account of the public interest in maintaining a confidential medical service, or appropriately considered the ethical implications of its decision;
- there has been inadequate consultation on the practice of data-sharing, and the concerns of the General Medical Council and the National Data Guardian have not been adequately addressed;
- data-sharing is taking place in a manner which is incompatible both with the guidance on confidentiality given by the GMC and the NHS Code of Confidentiality; and
- the advice given by the Government’s statutory public health adviser, Public Health England— “the perceived or actual sharing of identifiable information from confidential health records in order to trace individuals in relation to possible immigration offences [...] could present a serious risk to public health and has the potential to adversely impact on the discharge by PHE of the Secretary of State’s statutory health protection duty”—has been ignored.

¹⁰ <https://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2017/mou-data-sharing-nhs-digital-home-office-inquiry-17-19/publications/> (HC 677)

15. We concluded

For those reasons, we request that NHS Digital suspend the MoU immediately, and undertake a further and more thorough review of the public interest test. In order to ensure that there is no continued conflict between the standards of confidentiality applied in different parts of the health system, consideration of the public interest test, and whether the arrangements set out in the memorandum of understanding should be resumed, should not be undertaken until NHS England's review of the NHS Code of Confidentiality is complete.^[11] The decision about the application of the public interest test should be undertaken in the light of the reviewed Code, and the sharing of data held by the NHS for immigration enforcement should not be resumed in the meantime. Furthermore, the decision about the application of the public interest test should be taken in the light of public consultation, and with the full participation of both the General Medical Council and the National Data Guardian.

16. We went on to point out that “the evidence which has been presented to us in the course of our brief inquiry suggests very strongly [...] that the public interest in the disclosure of information held by the NHS is heavily outweighed by the public interest in the maintenance of a confidential medical service”, and we expressed our disappointment about NHS Digital's approach to the issue. We noted NHS Digital's duty, under section 253(1)(ca) of the Health and Social Care Act 2012, to have regard to “the need to respect and promote the privacy of recipients of health services”, and indicated that we expected NHS Digital to take the opportunity to demonstrate that it took its duties in respect of confidentiality seriously by listening to the concerns raised about the MoU and taking action accordingly.

Responses from Ministers and from NHS Digital

17. We received responses to that letter from Home Office and DHSC Ministers and from NHS Digital on Friday 23 February. They have also been published on our website.¹²

18. The letters rejected the case for suspending the memorandum of understanding. The Ministers' letter set out the policy considerations which underlay the arrangements in the MoU, and argued that our letter had not given due weight to the public policy objective of maintaining the effective enforcement of the UK's immigration laws. NHS Digital's response acknowledged the arguments made in the Ministers' reply, and noted that its “consistent conclusion has been that the public interest in supporting the effective enforcement of immigration law outweighs concerns that this minimal level data sharing in relation to this very tightly defined set of individuals might genuinely impact broader public trust in a confidential health service.”

11 For more about the review of the Code of Confidentiality, see paras 24 and 31ff. below.

12 <http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-and-social-care-committee/news/committee-publishes-responses-on-mou-17-19/>

19. In accordance with the final sentence of our letter to NHS Digital, we called its Chair and Chief Executive back to give further evidence on 15 March 2018. We indicated in our letter that they would be “required to provide a very much more convincing case for the continued operation of this MoU than has been presented so far.”

20. The transcript of that session is also available on our website.¹³

13 <https://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2017/mou-data-sharing-nhs-digital-home-office-inquiry-17-19/publications/>

Oral evidence in March 2018

21. The focus of our questioning on 15 March was on NHS Digital's role as a steward of health and social care data. We were looking for evidence that its Chair and Chief Executive understood that role, and were prepared to act in accordance with it. We regret that we found very little such evidence in the responses which they gave to our questioning.

Confidentiality

22. There is a longstanding principle that information collected for the purposes of healthcare is confidential. That principle was referred to in almost all the written submissions we received during this inquiry, but is perhaps most usefully expressed in Public Health England's submission to the NBO review, provided to our predecessors in March 2017:

Healthcare practitioners routinely advise patients that information provided is confidential and that it will be shared only with their consent and/or to improve coordination of their care across teams and/or agencies. This is a fundamental principle of working with patients which ensures public confidence and is enshrined in the General Medical Council's Good Medical Practice, the NHS Constitution, and a wide range of guidance and policy documents from the Department of Health, Royal Colleges and third sector/voluntary agency advice to their clients.¹⁴

23. As a number of written submissions also pointed out, that confidentiality is not absolute. The NHS Code of Practice: Confidentiality, the General Medical Council's Guidance on Confidentiality, and *A guide to confidentiality in health and social care*, published by NHS Digital itself, all acknowledge that confidential information can be disclosed to support the detection, investigation and punishment of serious crime. We support that position, and agree that it is entirely appropriate for NHS Digital to share information with law enforcement agencies, on a case-by-case basis, in cases of serious crime (such as the sex offender referred to in the Ministers' response to our letter of 29 January).

24. NHS Digital's letter of 23 February explains the problem which arises in connection with the data-sharing governed by this memorandum of understanding, and its response:

As I said at the 16 January hearing, I share your concern that there is a difference between i) the legal bases for disclosure in the Health and Social Care Act 2012, ii) the guidance for disclosure contained in the NHS Code of Practice: Confidentiality (2003), and iii) the General Medical Council's Guidance on Confidentiality (2009 and updated 2017). The key area of concern is that these guidance documents advise that information may be disclosed in relation to the detection, investigation or punishment of serious crime, whereas the Health and Social Care Act 2012 (section 261(5)(e)) permits disclosure where it is made "in connection with the investigation of a criminal offence" (not requiring an assessment of the 'seriousness' of that

¹⁴ <https://www.parliament.uk/documents/commons-committees/Health/Correspondence/2016-17/Correspondence-Memorandum-Understanding-NHS-Digital-Home-Office-Department-Health-data-sharing.pdf>, p.22.

offence). Your committee noted that NHS England is undertaking a review of the NHS Code of Practice: Confidentiality which may result in greater alignment of the Code of Practice with the statute.

Nevertheless, NHS Digital has considered the matter carefully, concluding that the data sharing is lawful and proportionate in relation to the immigration offences. Case law confirms that the common law right to confidentiality is not absolute, and the law recognises the need for a balancing exercise between this right and other competing rights and interests. In the Court of Appeal case of *W, X, Y and Z* [2015] EWCA Civ 1034, one of the reasons for weighing the balance in favour of disclosure was that the nature of the information in question was considered by the court to be “low on the spectrum of confidential information” (para 85). Our view is that the Home Office requesting disclosure of non-clinical administrative information such as address details (or simply confirmation of information it already has) falls at the less intrusive end of the spectrum. This is one of the factors leading us to conclude that the Home Office’s request is proportionate.

25. In addition to the concerns expressed by a wide range of non-governmental organisations, including the British Medical Association Medical Ethics Committee,¹⁵ we received representations from both the General Medical Council¹⁶ and the National Data Guardian for health and social care concerning NHS Digital’s approach to the sharing of these data. Dame Fiona Caldicott, the National Data Guardian, wrote to us following our 16 January oral evidence session as follows:

When NHS Digital consider releases of demographic data to police for law enforcement, it does apply a serious crime threshold. I have not seen a convincing explanation as to why the threshold that is described in published guidance is not applied to releases of data to the Home Office for the purposes of immigration enforcement.¹⁷

Ahead of our 15 March session, Dame Fiona told us “I continue to feel that the key concerns expressed by your committee, my panel and I, and organisations such as the General Medical Council, British Medical Association, Royal College of General Practitioners, and knowledgeable charities, have not yet been sufficiently addressed.”¹⁸

26. Following the 15 March session, we consider that those concerns remain insufficiently addressed. NHS Digital’s reliance on the case of *W, X, Y and Z* is unconvincing—indeed troubling. Para 46 of the judgement in that case says:

The present case is concerned with a particular regime under which patients are usually informed that the limited details contained in the Information may be disclosed to a limited class of persons for a particular reason connected with immigration control. It should not be seen as a Trojan

15 [MOU0015](#)

16 [MOU0006](#)

17 [MOU0011](#)

18 [MOU0016](#)

horse which will lead to the dismantling of the principle that information about a person's health and medical treatment is inherently private and confidential.¹⁹

It is very concerning that that case should now be being used as precisely the kind of "Trojan horse" to which the court referred.

Consultation

27. In our letter of 29 January, we argued that there had been inadequate consultation on the arrangements set out in the MoU. Following the responses from the Ministers and from NHS Digital, and the further evidence session on 15 March, we remain of that view.

28. The Ministers' response is particularly woeful, suggesting that our view was that "the MOU [...] should have been the subject of public consultation, including with NHS practitioners and the NGO community".²⁰ In fact, we stated explicitly that "it is not the MoU itself on which full consultation should have taken place, but on the practice of data-sharing for immigration enforcement which it enshrined." Ministers, it seems, continue "wholly to miss the point."²¹

29. NHS Digital, meanwhile, continued both in its written response to our 29 January letter and in oral evidence on 15 March to maintain that its consultation on the NBO review had been sufficient to address the issues raised by the practice of data-sharing for immigration tracing purposes.²² Written submissions we received both before and after our hearings make a very clear case that that is not so.²³

30. It is also regrettable that NHS Digital has not consulted medical ethicists on the appropriateness and implications of the data-sharing practices enshrined in the MoU.²⁴

NHS Code of Confidentiality

31. The review of the NHS Code of Confidentiality currently being undertaken by NHS England is a very important piece of work which needs to be conducted with great care, full consideration of all the implications, and wide and proper consultation of a kind which has not been undertaken in the case of this MoU. It will be particularly important that the review seeks, and takes account of, the views of medical ethicists on the Code, and on any proposed revisions.

32. For the time being, however, **the principle remains in place that data held for the purposes of health and care should only be shared for law enforcement purposes in the case of serious crime. It is not only the GMC and NHS Codes which reflect this**

19 <https://www.judiciary.gov.uk/wp-content/uploads/2015/10/w-x-y-z.pdf> [accessed 24.03.18]

20 <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>

21 See Appendix 1

22 Q127ff.

23 [MOU0003](#), [MOU0019](#)

24 Q120f.

principle, but even NHS Digital’s own guidance on confidentiality.²⁵ It is entirely inappropriate that NHS Digital should be sharing data in a manner inconsistent with that principle.

33. Furthermore, NHS Digital’s decision to share information with the Home Office under the MoU is not in accordance with the statement on its website that its information is “only ever used for the good of health and care”.²⁶ NHS Digital cannot continue to maintain that statement in the face of this data-sharing arrangement. That calls into question its ability to act according to that principle in the rest of its work.

NHS Digital’s approach to the issue

34. The performance of the Chair and Chief Executive of NHS Digital when they appeared before us on 15 March showed that NHS Digital has taken a highly process-driven approach, focussed narrowly on legal considerations without due regard to wider concerns about ethics and public confidence.²⁷ We do not consider that to be an appropriate basis on which to deal with the matter of the sharing of patient data.

35. NHS Digital’s Chair referred to his organisation’s “obligation” to provide information under section 261(5) of the Health and Social Care Act 2012.²⁸ That provision, however, confers a power, not an obligation. The National Data Guardian told us

In the NHS Digital submission to your committee I noted that it states:

“Our public interest test does not take into consideration whether the alleged crime is serious. This is **because** the legal gateways used for the release of data, particularly s.261(5) of the Health and Social Care Act 2012, do not limit consideration of criminal offences only to serious crimes.”
[Bold emphasis added]

However, I believe it to be the case that the legal gateway being used in the Health and Social Care Act should be considered as a necessary, but not sufficient, hurdle to be passed before the information is disclosed. As the relevant clauses of the Act make clear, the requirement to consider the Common Law Duty of Confidence remains. It is my opinion that the different requirements of the statute and the common law are not unhelpful inconsistencies to be solved or removed, but rather two standards, both of which must be satisfied.²⁹

36. We remain disappointed, as we said in our 29 January letter, that NHS Digital is approaching this matter as one of “simply [seeking] to exercise our statutory duty”. The written and oral evidence given to us in the course of this inquiry presents a wide range of ethical and practical implications of the practice enshrined in the MoU, implications which the Chair and Chief Executive have shown only the dimmest ability to comprehend and assess. The clearest example of that came in the response to our invitation for them

25 [A guide to confidentiality in health and social care](#), Health and Care Information Centre (now known as NHS Digital), September 2013.

26 <https://digital.nhs.uk/about-nhs-digital/our-work> [accessed 24.03.18]

27 See, in particular, Q122ff.

28 Q99

29 [MOU0011](#)

to advise on whether an individual medical practitioner should inform their patients that their information might be shared in this way. It is extraordinary that—despite the inability of the Health and Social Care Minister, Lord O’Shaughnessy, to answer the same question in our earlier evidence session, a failure to which we drew attention in our 29 January letter—the Chair of NHS Digital remained unable to answer.³⁰

37. The leadership of NHS Digital has not been sufficiently robust in upholding the interests of patients or in maintaining the necessary degree of independence from Government. It is deeply concerning that so little regard was paid by either the Chair or the Chief Executive to the underlying ethical implications that arise from the MoU. At a time when the benefits of data sharing for research is such a key issue, it is absolutely crucial that the public have confidence that those at the top of NHS Digital have both an understanding of the ethical underpinning of confidentiality and the determination to act in the best interests of patients.

Government policy on the sharing of patient data

38. The Ministers’ response to our 29 January letter contains the following statement:

It is also important to consider the expectations of anybody using the NHS—a state-provided national resource. 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.

39. In a supplementary submission to our inquiry, National Aids Trust comment

This is a very revealing and disquieting passage. It for a start makes clear the Government’s view that non-clinical information held by the NHS should be available to the rest of Government whenever they are acting ‘in the exercise of their lawful powers’. [...] The implications are enormous. As worrying is the argument that such access is a quid pro quo for the state providing a tax-funded NHS. We are not aware of any such ‘contract’ in the founding of the NHS—the benefit to Government is to have a healthy population, not to secure a database of personal information to mine for whatever purposes the Government sees fit.³¹

40. The Chair of the BMA Medical Ethics Committee expanded further on that concern:

Whilst the MoU relates only to information about immigration offenders, it could be used to set a precedent which allows confidentiality to be set aside in the interest of political decisions. As was highlighted by a witness in the last evidence session, “to date, the criteria that apply for breaching that confidentiality are ethical criteria, not political criteria”. A direction of

30 Q160

31 [MOU0014](#)

travel in which data-sharing arrangements are justified or rationalised on a political basis wholly undermines the ethical framework in place to ensure there is a balanced judgment made in situations of competing priorities.

He went on to refer to the statement in the Ministers' letter as a "deeply concerning approach".³²

41. These concerns are not mere scaremongering. Ahead of the 15 March hearing, NHS Digital presented us with the early results of polling which it had carried out "as part of [its] ongoing assessment of the appropriateness of NHS Digital's sharing of personal demographic data with the Home Office for the purpose of tracing individuals suspected of immigration offences".³³ The questions asked as part of that polling show that the possibility of sharing demographic data with other Government departments in cases of tax evasion, benefits fraud or theft is already being contemplated by NHS Digital. NHS Digital's Chair's claim that "it would be unusual if we were requested by another Government Department to follow the process that we have adopted with the Home Office for immigration offences; [...] we have had no requests as such and we do not expect requests as such to come from other Departments that might require us to put in place a similar arrangement to the one we have today" offers little reassurance in the face of the Ministers' statement of Government policy on the use of NHS data.³⁴

42. We are deeply concerned that accepting the Government's stated position would lead to sharing non-clinical data such as addresses with other Government departments. We believe that patients' addresses, collected for the purposes of health and social care, should continue to be regarded as confidential.

The role of NHS Digital

43. The Health and Social Care Act 2012 established NHS Digital as a non-departmental public body, at arm's length from Government. It therefore has the ability—and, we argue, the duty—to stand up to Government robustly in the interests of patient confidentiality, and to protect the public's health data from the encroachment of Government. That duty is reflected in the statutory requirement for NHS Digital to have regard to "the need to respect and promote the privacy of recipients of health services".³⁵ In cases where the Secretary of State feels that NHS Digital is not acting sufficiently in accordance with Government policy, he has the power under the Health and Social Care Act 2012 to give directions, so NHS Digital is not able to frustrate Government policy. What it can, and should, do is ensure that, unless specifically instructed otherwise, it acts in accordance with its remit to protect patient data and share it only for the good of health and care. Where, as in the case of this MoU, Government requires of NHS Digital something which is runs contrary to the longstanding policy of the NHS, as reflected in NHS Digital's own guidance, its inability to say no is deeply worrying.

32 [MOU0015](#)

33 [MOU0017](#)

34 Q160

35 Health and Social Act 2012 (as amended), section 253(1)(ca).

44. We support the sharing of data for the benefit of patients, with their consent. As demonstrated by the care.data experience,³⁶ the success of such data-sharing depends crucially on public consent and confidence in NHS Digital's commitment to respecting confidentiality. Its actions in this case risk undermining that confidence.

36 See <http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/inquiries/parliament-2010/cdd-2014/>

Action required

The memorandum of understanding and the public interest test

45. We repeat the conclusion of our 29 January letter that NHS Digital should suspend its participation in the memorandum of understanding. In order to ensure that there is no continued conflict between the standards of confidentiality applied in different parts of the health system, consideration of the public interest test, and of whether the arrangements set out in the memorandum of understanding should be resumed, should not be undertaken until NHS England's review of the NHS Code of Confidentiality is complete. The decision about the application of the public interest test should be undertaken in the light of the reviewed Code, after proper consultation with all interested parties on the specific practice of data-sharing for the purposes of immigration tracing, and with the full involvement of experts in medical ethics.

Risks to public health

46. Reconsideration of the public interest test will also require reconsideration of the risks to public health posed by sharing data with the Home Office for immigration tracing purposes. In our letter of 29 January, we noted that the advice from the Government's statutory advisers on public health, Public Health England (PHE), was very clear: "the perceived or actual sharing of identifiable information from confidential health records in order to trace individuals in relation to possible immigration offences [...] could present a serious risk to public health and has the potential to adversely impact on the discharge by PHE of the Secretary of State's statutory health protection duty". We remain of that view, and consider that the evidence presented by PHE should have been taken more seriously when the public interest test was conducted.

47. We argued that the commissioning of PHE to carry out a further evidence review appeared to be little more than window-dressing. Given the clarity of the evidence originally presented, and the difficulty of collecting "robust statistical evidence" about the effects of the MoU on a population—migrants with whom the Home Office has lost touch—which is by definition hard to reach, we remain unconvinced of the value of the exercise on which PHE is now engaged.

48. Nevertheless, we hope that any evidence Public Health England might be able to collect will add to the weight of the evidence already available on the deterrent effect on this vulnerable population to seeking healthcare which is crucial to avoiding the potential spread of communicable diseases. **We recommend that when it reports at the conclusion of its review of the evidence of the impact of the MoU on health-seeking behaviours, Public Health England (PHE) restate its conclusion on the basis of the evidence already available, and then report on whether its further research has collected any evidence which would be sufficient to change the view it had already reached. The reassessment of the public interest test carried out once the review of the NHS Code of Confidentiality is complete should take into account—and give proper weight to—all the evidence PHE presents.**

Government policy on sharing of data held for the purpose of health and care

49. **The review of the NHS Code of Confidentiality should also consider and consult upon the statement of Government policy on data-sharing which was contained in the Ministers' response to our letter of 29 January, and advise Ministers on whether it is an appropriate statement of policy on the sharing of data collected and held for the purpose of health and care.**

Conclusions and recommendations

NHS Digital's approach to data-sharing for immigration tracing

1. The principle remains in place that data held for the purposes of health and care should only be shared for law enforcement purposes in the case of serious crime. It is not only the GMC and NHS Codes which reflect this principle, but even NHS Digital's own guidance on confidentiality. It is entirely inappropriate that NHS Digital should be sharing data in a manner inconsistent with that principle. (Paragraph 32)
2. The leadership of NHS Digital has not been sufficiently robust in upholding the interests of patients or in maintaining the necessary degree of independence from Government. It is deeply concerning that so little regard was paid by either the Chair or the Chief Executive to the underlying ethical implications that arise from the MoU. At a time when the benefits of data sharing for research is such a key issue, it is absolutely crucial that the public have confidence that those at the top of NHS Digital have both an understanding of the ethical underpinning of confidentiality and the determination to act in the best interests of patients. (Paragraph 37)
3. We support the sharing of data for the benefit of patients, with their consent. As demonstrated by the care.data experience, the success of such data-sharing depends crucially on public consent and confidence in NHS Digital's commitment to respecting confidentiality. Its actions in this case risk undermining that confidence. (Paragraph 44)

The memorandum of understanding and the public interest test

4. We repeat the conclusion of our 29 January letter that NHS Digital should suspend its participation in the memorandum of understanding. In order to ensure that there is no continued conflict between the standards of confidentiality applied in different parts of the health system, consideration of the public interest test, and of whether the arrangements set out in the memorandum of understanding should be resumed, should not be undertaken until NHS England's review of the NHS Code of Confidentiality is complete. The decision about the application of the public interest test should be undertaken in the light of the reviewed Code, after proper consultation with all interested parties on the specific practice of data-sharing for the purposes of immigration tracing, and with the full involvement of experts in medical ethics. (Paragraph 45)

Risks to public health

5. In our letter of 29 January, we noted that the advice from the Government's statutory advisers on public health, Public Health England (PHE), was very clear: "the perceived or actual sharing of identifiable information from confidential health records in order to trace individuals in relation to possible immigration offences [...] could present a serious risk to public health and has the potential to adversely impact on the discharge by PHE of the Secretary of State's statutory health protection

duty”. We remain of that view, and consider that the evidence presented by PHE should have been taken more seriously when the public interest test was conducted. (Paragraph 46)

6. We recommend that when it reports at the conclusion of its review of the evidence of the impact of the MoU on health-seeking behaviours, Public Health England (PHE) restate its conclusion on the basis of the evidence already available, and then report on whether its further research has collected any evidence which would be sufficient to change the view it had already reached. The reassessment of the public interest test carried out once the review of the NHS Code of Confidentiality is complete should take into account—and give proper weight to—all the evidence PHE presents. (Paragraph 48)

Government policy on sharing of data held for the purpose of health and care

7. The review of the NHS Code of Confidentiality should also consider and consult upon the statement of Government policy on data-sharing which was contained in the Ministers’ response to our letter of 29 January, and advise Ministers on whether it is an appropriate statement of policy on the sharing of data collected and held for the purpose of health and care. (Paragraph 49)
8. We are deeply concerned that accepting the Government’s stated position would lead to sharing non-clinical data such as addresses with other Government departments. We believe that patients’ addresses, collected for the purposes of health and social care, should continue to be regarded as confidential. (Paragraph 42)

Appendix: Letter from the Chair of the Committee to the Chief Executive of NHS Digital, 29 January 2018

Sarah Wilkinson
Chief Executive, NHS Digital

Dear Ms Wilkinson,

Thank you for attending the hearing of the Health Committee on 16 January to discuss the memorandum of understanding between NHS Digital, the Home Office and the Department of Health on processing information requests from the Home Office to NHS Digital for tracing immigration offenders.

We were pleased to hear you affirm, in answer to Dr Williams's final question (Q94), that the decision as to whether the data-sharing arrangement should continue lies firmly with NHS Digital. I write on behalf of the Committee, in light of the evidence which we have received in the course of our inquiry, to request that NHS Digital immediately withdraw from the memorandum of understanding, and cease sharing data with the Home Office for immigration tracing purposes, whilst it conducts a full review of its decision on the public interest test for such requests.

Background to the tracing arrangements

As a Committee, we accept that the Home Office has a responsibility to seek to identify immigration offenders, to re-establish contact with them, and to take the required enforcement action.

We understand why the Home Office seeks information to enable it to carry out its immigration enforcement role. NHS Digital, and its predecessor organisations, undoubtedly hold information which the Home Office would view as useful. However, the NHS should not place that above the serious adverse consequences of such a decision.

As your senior non-executive director Sir Ian Andrews acknowledged (Q89), these arrangements had produced a "haphazard" process. Our predecessor Committee's work in 2014 also identified that point, and NHS Digital established a review in response. The review has resulted in many changes to practice and procedure in NHS Digital's "back office" functions.

Public interest

However, the evidence which we have received makes very clear that the review has not adequately addressed the fundamental question of whether the arrangements for data sharing for immigration purposes, which had grown up in the haphazard way described by Sir Ian and without consideration of their appropriateness in a wider context, should

continue. Specifically, we do not believe that NHS Digital has fully considered and appropriately taken account of the public interest in maintaining a confidential medical service, or appropriately considered the ethical implications of their decision.

Inadequate consultation

The submissions which have been sent to us indicate that not only was there inadequate consultation with concerned non-governmental organisations such as the National Aids Trust and Doctors of the World, but more seriously, the concerns of both the General Medical Council (GMC) and the National Data Guardian (NDG) about the practice now enshrined in the memorandum of understanding have not been adequately addressed. We also find it disturbing that the matter has not been considered by NHS Digital's own Independent Group Advising on the Release of Data (IGARD) (Q1).

The inadequacy of the consultation with bodies and individuals concerned about confidentiality is apparent throughout the submissions which we have received. It is most clearly demonstrated, however, by the fact that, despite the five paragraphs in the memorandum of understanding devoted to public interest in disclosing information for the purposes of immigration enforcement, there is no mention anywhere in the MoU of the public interest in the maintenance of a confidential medical service.

It is unfortunate that, throughout both our and our predecessors' scrutiny of this matter, both NHS Digital and the Department of Health have continued to maintain that consultation on the memorandum of understanding was unnecessary, or would have been inappropriate, because it was merely an "internal governance assurance document" which "represents the operationalisation of existing functions". That is wholly to miss the point. It is not the MoU itself on which full consultation should have taken place, but on the practice of data-sharing for immigration enforcement which it enshrined. That full consultation clearly has not taken place.

Compatibility with guidance on confidentiality

This lack of consultation has resulted in a situation where data-sharing is taking place in a manner which is incompatible both with the guidance on confidentiality given by the GMC and the NHS Code of Confidentiality. We find that situation unacceptable. The Minister's inability to respond to our questioning about whether clinicians should be expected to inform their patients that their names and addresses might be shared with the Home Office (Qq 33–36) was telling. So is the fact that NHS Digital does not, so we understand, involve clinicians within the organisation, including its own Caldicott Guardian and Deputy Caldicott Guardian, in decision-making on these requests, in order to protect them from the risk that in so doing they would be acting in conflict with the GMC's confidentiality guidance. National Data Guardian Dame Fiona Caldicott observes—with, we believe, understatement—that "if an organisation in the NHS family such as NHS Digital considers it necessary to make arrangements so that doctors, including its most senior staff responsible for protecting confidentiality, do not take part in decision-making, particularly in an area on which they might be expected to give advice, because doing so might place them in breach of professional confidentiality guidelines, this could be taken to be an indication that there is a problem."

Advice from Public Health England

We are also concerned that the advice of the one organisation in the health field who was appropriately consulted, the Government’s statutory public health adviser Public Health England, has been so comprehensively ignored. PHE’s advice was very clear: “the perceived or actual sharing of identifiable information from confidential health records in order to trace individuals in relation to possible immigration offences [. . .] could present a serious risk to public health and has the potential to adversely impact on the discharge by PHE of the Secretary of State’s statutory health protection duty”. The reference, in the National Back Office review report, to a lack of “robust statistical evidence” as a justification for rejecting PHE’s advice is wholly unconvincing. Still less convincing as a justification is NHS Digital’s invocation of “the potential harm that might arise by not processing these tracing requests, i.e. an individual would be out in the community without appropriate support for longer”. The purpose of tracing is not to provide these individuals with medical assistance but to take enforcement action, presumably leading to deportation, and it seems to us to be misleading to include this point. As Dame Fiona Caldicott has observed, “the evidence presented by colleagues from Public Health England and the voluntary and charity sector that undocumented migrants are deterred from seeking healthcare for the fear that information about them will be shared with other parts of Government is convincing, and appears to be considerably more substantial than the evidence available about the benefit of these disclosures”.

In this context, the commissioning of PHE to carry out a further evidence review appears to be little more than window-dressing. Given the nature of the population about whom this further evidence is intended to be sought, we doubt that the kind of data which NHS Digital is demanding is even capable of being collected. As Yusef Azad of NAT told us (Q16), “The irony is not lost on us, to be asked for statistical evidence by a tracing service desperately trying to find the basic whereabouts of thousands of migrants every year. The Home Office itself does not have robust statistical evidence around undocumented migrants. That is the problem.” Witnesses at our hearing provided accounts of individuals already being deterred from seeking help and NHS Digital needs to take a precautionary approach. Absence of evidence is not evidence of absence when it comes to assessing an avoidable risk of communicable diseases going untreated.

Suspension of the MoU

For those reasons, we request that NHS Digital suspend the MoU immediately, and undertake a further and more thorough review of the public interest test. In order to ensure that there is no continued conflict between the standards of confidentiality applied in different parts of the health system, consideration of the public interest test, and whether the arrangements set out in the memorandum of understanding should be resumed, should not be undertaken until NHS England’s review of the NHS Code of Confidentiality is complete. The decision about the application of the public interest test should be undertaken in the light of the reviewed Code, and the sharing of data held by the NHS for immigration enforcement should not be resumed in the meantime. Furthermore, the decision about the application of the public interest test should be taken in the light of public consultation, and with the full participation of both the General Medical Council and the National Data Guardian.

Our evidence on the public interest test

The evidence which has been presented to us in the course of our brief inquiry suggests very strongly—contrary to your own assessment—that the public interest in the disclosure of information held by the NHS is heavily outweighed by the public interest in the maintenance of a confidential medical service. The evidence of harm both to individuals and to health-seeking behaviour, with its potentially serious implications for public health, and to the patient-clinician relationship, which depends crucially on trust, is tangible. Furthermore, the practice of sharing data for immigration tracing purposes—even data at what the Minister referred to as “the low end of the spectrum of confidentiality”—has significant implications for public confidence generally in the confidentiality of health data. It is vitally important that the public has confidence in the handling of data held by the NHS, so that it can be shared in circumstances where there are genuine benefits to the health and wellbeing of individuals and the population. Those reasons alone are sufficient, in our view, to justify the suspension of the MoU until the implications of the practice of sharing these data have been fully explored.

NHS Digital’s duties

We are deeply disappointed that NHS Digital has until now approached this matter as one of “simply [seeking] to exercise our statutory duty”. We note the view of the National Data Guardian that “the legal gateway being used in the Health and Social Care Act should be considered as a necessary, but not sufficient, hurdle to be passed before the information is disclosed”. We further note that NHS Digital is also subject to the duty, under section 253(1)(ca) of the Health and Social Care Act 2012, to have regard to “the need to respect and promote the privacy of recipients of health services”.

We now expect NHS Digital to take this opportunity to demonstrate that it takes its duties in respect of confidentiality seriously by listening to the concerns raised about the MoU and taking action accordingly. If it does not, we will expect to hold a further evidence session, where you will be required to provide a very much more convincing case for the continued operation of this MoU than has been presented so far.

Yours sincerely,

Dr Sarah Wollaston MP

Chair of the Committee

Formal minutes

Wednesday 28 March 2018

Members present:

Dr Sarah Wollaston, in the Chair

Luciana Berger	Derek Thomas
Rosie Cooper	Andrew Selous
Diana Johnson	Martin Vickers
Johnny Mercer	Dr Paul Williams

Draft Report (*Memorandum of understanding on data-sharing between NHS Digital and the Home Office*), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 49 read and agreed to.

Summary agreed to.

A paper was appended to the Report as Appendix 1.

Resolved, That the Report be the Fifth Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned till Tuesday 17 April at 1.45pm.]

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the [inquiry publications page](#) of the Committee's website.

Tuesday 16 January 2018

Yusef Azad, Director of Strategy, National AIDS Trust, **Dr Joanne Bailey**, Member of the Advisory Panel, National Data Guardian, **Marissa Begonia**, Coordinator, the Voice of Domestic Workers, **Dr Lucinda Hiam**, General Practitioner, Doctors of the World, and **Professor John Newton**, Director of Health Improvement, Public Health England

[Q1–31](#)

Lord O'Shaughnessy, Parliamentary Under-Secretary of State for Health (Lords), Department of Health, **Sir Ian Andrews**, Non-executive Director, NHS Digital, **Sarah Wilkinson**, Chief Executive Officer, NHS Digital, **Caroline Nokes**, Minister for Immigration, Home Office, **Jonathan Marron**, Director General, Community Care, Department of Health, and **Hugh Ind**, Director General of Immigration Enforcement, Home Office

[Q32–94](#)

Thursday 15 March 2018

Sarah Wilkinson, Chief Executive Officer, NHS Digital, and **Noel Gordon**, Chair, NHS Digital

[Q95–171](#)

Published written evidence

The following written evidence was received and can be viewed on the [inquiry publications page](#) of the Committee's website.

MOU numbers are generated by the evidence processing system and so may not be complete.

- 1 British Medical Association ([MOU0015](#))
- 2 Amnesty International UK ([MOU0010](#))
- 3 British Medical Association ([MOU0005](#))
- 4 Doctors of the World UK ([MOU0019](#))
- 5 General Medical Council ([MOU0006](#))
- 6 Just Fair ([MOU0007](#))
- 7 medConfidential ([MOU0018](#))
- 8 National AIDS Trust ([MOU0002](#))
- 9 National AIDS Trust ([MOU0003](#))
- 10 National AIDS Trust ([MOU0009](#))
- 11 National AIDS Trust ([MOU0014](#))
- 12 National Data Guardian ([MOU0011](#))
- 13 National Data Guardian ([MOU0016](#))
- 14 NHS Digital ([MOU0004](#))
- 15 NHS Digital ([MOU0017](#))
- 16 Sarah Wilkinson, CEO, NHS Digital ([MOU0013](#))
- 17 Sir Ian Andrews, Senior Independent Director, NHS Digital ([MOU0012](#))

List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the [publications page](#) of the Committee's website. The reference number of the Government's response to each Report is printed in brackets after the HC printing number.

Session 2017–19

First Report	Appointment of the Chair of NHS Improvement	HC 479
Second Report	The nursing workforce	HC 353
Third Report	Improving air quality	HC 433
Fourth Report	Brexit: medicines, medical devices and substances of human origin	HC 392
First Joint Special Report	Children and young people's mental health—the role of education: Government Response to the First Joint Report of the Education and Health Committees of Session 2016–17	HC 451