Monday 6 March 2017

Dear Dr Wollaston,

Thank you for your letter requesting further clarification and information about the Memorandum of Understanding between the Department of Health (DH), NHS Digital (NHSD) and the Home Office (HO), in relation to tracing requests from the Home Office to NHS Digital.

The decision to formalise existing processes into an MOU was made following a review of NHS Digital’s National Back Office function, which includes tracing services using administrative and non-clinical NHS data.

This review was led by Professor Maria Goddard a non-Executive member of NHS Digital’s Board. The review was initiated in November 2014 and involved close engagement with a range of internal and external stakeholders. The review has sought to examine existing processes, to consider concerns arising from the earlier Partridge Review and, in light of the Health and Social Care Act, 2012, to review the legal bases for sharing the information. A final objective has been to identify any areas for improvement and identify where a change in practice was required.

This in depth review will be published shortly and I can assure you that the MOU has been developed under appropriate scrutiny and with respect for the principles of confidentiality and legal data sharing. We have formalised and refined an information exchange between the NHS and HO which has been ongoing for many years to ensure that it is both proportionate and within an appropriate legal framework.

We will be publishing the full review in due course but, in the meantime, I hope that the responses in the Annex will answer your questions more fully.

Noel Gordon
Chairman
NHS Digital
Annex One

Impact assessments

1. Was any impact assessment carried out before the memorandum of understanding was agreed? In particular, was (a) an equality impact assessment and (b) a privacy impact assessment carried out? If not, why were such assessments not carried out? If so, please could you supply the Committee with copies of these assessments.

The Memorandum of Understanding (MOU) does not involve the NHS giving the Home Office any more information than has previously been the case, but it does formalise those arrangements and enables efficiencies because one NHS organisation, NHS Digital, can conduct a trace, rather than it being undertaken by a combination of national and local NHS organisations. In the past NHS Digital provided a trace which showed the area where someone was registered as a patient, and local NHS organisations were then contacted by the Home Office directly and asked to provide an address.

The approach governed by the MOU no longer requires involvement from local NHS services so reduces the administrative burden and duplication, and ensures that all requests are processed using transparent and standardised procedures. I would like to re-assure you that no medical data (sensitive personal data) is being requested by or released to the Home Office.

Privacy Impact Assessments (PIA) are a useful tool to identify, assess and mitigate the risks to privacy associated with new projects and or initiatives. NHSD carries out a public interest test for each specific request, to establish whether the information should be released (see para 7.8 - 7.12 of the MoU for further information). This test includes an assessment of the privacy implications and the competing public interest for and against the disclosure of the information to the HO on a case by case basis. As a public interest test is carried out in each individual case, a PIA was not undertaken as it would not have provided any additional assurance in this instance. However privacy considerations were fully assessed as part of putting in place the MOU.

Equality Impact Assessment

The Department of Health (DH) carried out the following assessments when considering the impact of the Memorandum of Understanding:

Due regard to the public sector equality duty (PSED) under section 149 of the Equality Act 2010, when carrying out a public function. DH considered the potential impact on groups sharing a protected characteristic under the Equality Act 2010. DH was conscious of the legal requirement that the data sharing protocol must not unlawfully discriminate, or create barriers to advance equality of opportunity and foster good relations between those sharing protected characteristics and those who do not.

DH worked with Home Office (HO) and NHS Digital to satisfy itself that there is a substantial public interest in sharing this non-clinical information to support effective immigration enforcement. The approach we have taken to clarify the legal basis for these limited data
exchanges has considered the impact on particular groups who could be affected by the protocol such as vulnerable children and adults. DH satisfied itself that the agreed protocol was in compliance with the Equality Act 2010.

Section 1 of the NHS Act 2006, in particular the requirement for Secretary of State (SoS) to reduce health inequalities. DH demonstrated due regard through its work with Public Health England to explore use of available and/or planned research to support better awareness and understanding of the impact of government policy on immigration enforcement on migrants’ health behaviours and likelihood to seek treatment. DH is keeping this issue under close review, and as one of the outcomes of the review will be commissioning PHE to conduct research within the next two years.

Consultation
2. What consultation was carried out with (a) clinicians, (b) patient representative groups and (c) groups protecting the rights of migrants before the memorandum was agreed?

The MOU represents the operationalisation of existing functions, and reflects recommendations of the National Back Office Review therefore we did not consult on the MoU itself as it is an internal governance assurance document between DH, NHSD and the HO.

However, the MOU is one of the outcomes from the National Back Office Review, and as part of the review, there was engagement with representatives from bodies representing all of the groups above.

The Review team worked with and engaged a wide range of stakeholders during the review process, and this thinking and the views expressed influenced the findings and recommendations of the review.

The groups we engaged with represented patients, clinicians and groups protecting the rights of migrants and included:

Service Users:
- charities
- law enforcement bodies
- local authorities
- central government

Stakeholders:
- National Data Guardian
- Independent Information Governance Oversight Panel
- public health representatives
- civil liberties groups
- immigration support groups
Confidentiality

3. The Committee has been told that in the absence of a court order, the NHS does not share even the address of a patient with the police or any other public body, except in the most serious cases of harm to the person, involving murder, rape or manslaughter. Can you confirm that that is the case? What is the justification for adding immigration offences to the cases where confidential patient information may be shared?

It is not the case for demographic/administrative information that such information is shared solely in cases where there is ‘serious harm to the person’. For example NHS organisations are permitted to share patient address and associated administrative data for the purposes of recovering NHS debts and for the production of national statistics.

As per 1, the existence of the MOU does not fundamentally change the information that has historically been shared between the NHS and the Home Office, it simply streamlines the process to remove administrative burden, establish a consistent approach and ensures that the information exchange is proportionate and shared within an appropriate legal framework.

Prior to the MOU NHS Digital provided the details of the relevant local NHS organisation, and the local NHS organisation would provide demographic information that NHS Digital is now providing centrally. The MOU ensures that all requests are handled transparently, under the same rigorous scrutiny and with full understanding of the legal requirements.

In terms of tracing requests received from the Home Office, the Health and Social Care Act 2012 [s261] establishes a number of gateways which enable NHSD to disseminate (disclose) data subject to; consideration of the individual circumstance, the person to whom the information is disclosed and the purpose of the disclosure. This includes where required considering the public interests.

The s261 gateways do not constrain NHSD to considering only serious offences or harm to the person.

The MOU identified the applicable gateways which the parties considered to be relevant to the statutory purposes of HO Immigration. This includes Section 261(5)(e) which in the case of information considered to be confidential does require NHSD to consider the application of the common law if it would otherwise prohibit or restrict the disclosure. The common law duty of confidentiality and thus a public interest test is applied, weighing the public interest in favour and/or against a disclosure, and the MOU expresses how NHSD carries out this assessment.
It should be noted that the NHSD treats the administrative information as subject to the duty of confidentiality, notwithstanding that DH considers that such purely demographic/administrative information does not attract the duty of confidence.

Disclosures are also considered with reference to NHS Digital’s general duties, including having regard to the need to respect and promote the privacy of patients and the need to promote the effective, efficient and economic use of resources in the provision of health services and of adult social care.

As disclosure of tracing data involves the disclosure of personal data, NHS Digital must also comply with its obligations under the Data Protection Act 1998 when considering any disclosure.

Each tracing request is considered separately on a case-by-case basis. With the exception of court orders, NHS Digital reserves the right to refuse a tracing request and the MOU does not fetter NHSDs authority in this regard.

Where a request is accepted, it is assessed using the legal framework and the specific parameters and approval criteria outlined in the MOU.

As part of close work between DH, NHSD and HO to clarify the data flow, it has been identified that the NHS Code of Confidentiality requires updating to correct an inaccurate presumption that the common law duty of confidentiality applies to demographic/administrative information, and also to update guidance on the public interest, including the scope of serious offences and other cases which may justify disclosure.

4. What assessment has been made of the compatibility of the arrangements set out in the memorandum with the General Medical Council guidance on the maintenance of confidentiality?

NHSD has considered the issue of confidentiality in great detail.

GMC guidance has relevance to doctors. The tracing service is not a service to which the GMC guidance applies.

NHSD carries out an assessment of the public interest, which is cleared by the organisation’s SIRO, and notes that the public interest is not limited only to assessment of harm to individuals, but can also take into account other harms and benefits to society which can outweigh the individual’s interest in keeping the information confidential, and that approach is not incompatible with the GMC guidance - see for example paragraph 37 of the GMC guidance.

1 The GMC guidance also states at section 37. “Personal information may, therefore, be disclosed in the public interest, without patients’ consent, and in exceptional cases where patients have withheld consent, if the benefits to an individual or to society of the disclosure outweigh both the public and the patient’s interest in keeping the information confidential. You must weigh the harms that are likely to arise from non-disclosure of
Notwithstanding, NHSD has considered its obligations in regard to the Department of Health’s NHS Code of Practice; Confidentiality 2003, as amended 2010 alongside statutory, judicial and common-law provisions. In particular this consideration noted that that the NHS Code of Practice is out of date, particularly in regard to the data disseminations provisions set out in the HSCA 2012.

This Review finding was shared with the DH which has agreed to commission an update of the NHS Code of Practice, which will lead to it being renewed.

5. What assessment has been made of the effect of the agreement of a memorandum on data-sharing between the Home Office and NHS Digital on wider patient perceptions of the confidentiality of patient data?

NHS Digital considers public trust in its safe haven status to be essential in enabling it to operate effectively, for the benefit of patients, clinicians and the health and care system.

NHS Digital has published information about all of its tracing requests since April 2013. This is part of our transparency agenda, but the rules and guidance surrounding such requests have not previously been subject to the same clarity.

The MOU protocol between NHS Digital, the Department for Health and the Home Office formalises arrangements and sets out the business operating rules and legal framework under which services to Home Office are provided. This publicly available document is open to scrutiny from all interested parties and we welcome any feedback from our stakeholders.

Patient and public health

6. What assessment has been made of the effect of the arrangements set out in the memorandum on the (a) likelihood of vulnerable people failing to access healthcare and (b) the cost to the NHS and impact on the health of affected individuals if they are deterred from seeking early treatment for serious health conditions as a result?

DH discussed the issue with PHE, and concluded that there was no clear statistical evidence of the impact of data sharing deterring immigrants seeking health services, it is noted however that the increased transparency enabled by the MOU and Review may itself have an effect, and therefore as an recommendation of the Review.

NHSD has recommended that within two years research is commissioned on the impact on public health and health seeking behaviour arising from the disclosure of administrative information in relation to the investigation of criminal offences, including immigration offences.

information against the possible harm both to the patient, and to the overall trust between doctors and patients, arising from the release of that information.”
7. What assessment has been made of the effect of the arrangements set out in the memorandum on public health—particularly with reference to the danger of the spread of communicable diseases as a result of patients not seeking treatment for fear of revealing their whereabouts to the immigration service?

NHSD considered this issue extensively, taking into account the views and concerns raised during our engagement with stakeholders who were either opposed to or in favour of tracing for this purpose.

We acknowledge these viewpoints in our review.

In light of the concerns expressed to NHSD, the review did consider whether NHS Digital should cease processing requests from the Home Office, or if it should limit the service. One of the conclusions reached was that by limiting the service we may add to the burden of frontline health and care organisations.

In terms of the potential for harm arising from people being deterred from seeking health care for fear of being traced (both in terms of harm to the individual and wider community), NHSD considered various factors. The review concluded that there is currently insufficient evidence of such harm to justify suspending tracing for this purpose when weighed against the potential harms that may arise from not enabling the HO to re-establish contact with individuals, enabling them to be appropriately supported or where necessary, enforcing immigration controls. Notwithstanding these considerations, NHSD also noted there are public interests in maintaining effective immigration control given the importance that Parliament places on the role of immigration enforcement.

NHSD does however recognise that this issue needs to be kept under close review to decide whether further evidence is needed and have included a recommendation about this in the review. NHSD has recommended that within two years research is commissioned on the impact on public health and health seeking behaviour arising from the disclosure of administrative information in relation to the investigation of criminal offences, including immigration offences.

NHSD will continue ensure that when considering public interests in relation to specific requests, it considers the potential for public health harm into its assessment.

Public scrutiny

8. We understand that prior communications between NHS Digital and the Department of Health and groups concerned about the arrangements for data-sharing between NHS Digital and the Home Office has resulted in commitments from NHS Digital and the Department of Health that any formal agreement would be subject to proper scrutiny. How have those commitments been fulfilled?

The findings and learning from the stakeholder engagement have fed into both the review and the MOU.
We welcome additional feedback from our stakeholders at any stage and have also requested the views of the National Data Guardian.
Thank you for your letter of 27 February 2017 which raised questions on behalf of the Health Select Committee about the Memorandum of Understanding (MoU) between the Home Office (HO) and NHS Digital (NHSD) with the aim of locating individuals suspected of immigration offences. The Department of Health (DH) is also a signatory to this MoU.

The MoU sets out the administrative arrangements between the HO and NHSD in relation to tracing requests. It helpfully clarifies and confirms the purpose and legal basis of the exchange of non-clinical information between NHSD and the HO to locate those suspected of committing immigration offences, the procedural steps and responsibilities of the three signatory parties. We have formalised and refined an information exchange which has been ongoing for many years between the NHS and HO to ensure that it is proportionate and within an appropriate legal framework.

Some background on why this MoU was developed should be helpful to you. The Health Select Committee expressed concerns on 25 February 2014\(^1\) regarding the transparency of data releases undertaken by the Information Centre, a predecessor organisation of the Health and Social Care Information Centre (HSCIC and now known as NHSD). In response, the NHSD Board requested that a review of all data releases\(^2\) approved by the HSCIC between 1 April 2005 and 31 March 2013 be undertaken. This review (the “Partridge Review”) led by a non-executive Director of NHSD’s Board, Sir Nick Partridge, was published in June 2014 and included a recommendation to review and publish policy, process and governance\(^3\) about the functions of the National Back Office (NBO) and to highlight that the NBO serviced

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\(^1\) [http://www.parliamentlive.tv/Event/Index/caeba2b2-71ff-40ce-b4f6-64fd01451ae6?in=15%3A49%3A30](http://www.parliamentlive.tv/Event/Index/caeba2b2-71ff-40ce-b4f6-64fd01451ae6?in=15%3A49%3A30)

\(^2\) Includes data releases outside the health family.

\(^3\) Recommendation 4 “That the HSCIC publishes its policy, process and governance for the release of data.” Review of data releases by the NHS Information Centre Sir Nick Partridge 17 June 2014
tracing requests\textsuperscript{4} which originated from outside the NHS/health family. These include requests where information is shared on reliance of the section 29(3) exemption under the Data Protection Act (DPA) 1998 (data processed for the purposes of the apprehension/prosecution of offenders or prevention/detection of crime) as well as court orders. In response, the NHSD Board committed to undertake a further review of the tracing service. This review (the "NBO Review") has been led by NHSD's non-executive Director Professor Maria Goddard and is due to be published shortly. The NBO Review considers this information exchange between the HO and NHSD.

Your letter referred to the MoU as tracing individuals "suspected of immigration offences". It would be helpful to clarify that the MoU is about locating immigrants who have lost touch with the HO, in order to re-establish contact and either remove them from the UK or otherwise regularise their stay. This includes tracing individuals where there is evidence to suspect that the individual has committed an immigration offence under section 24 or 24A of the Immigration Act 1971, which includes offences where the individual has:

- failed to comply with reporting restrictions (including any grant of bail, temporary admission or temporary release);
- absconded from port immigration control;
- escaped from detention;
- exceeded their time limit to stay in the UK;
- sought to obtain leave by deception.

Some of these individuals may present a risk to the public as a result of criminal offending behaviour. Some may be vulnerable (e.g. with mental health or other health conditions or young children).

In all cases, a tracing request will only be triggered when other avenues available to the authorities to locate the individual have been unsuccessful. It will only be initiated for those which the HO are actively dealing with as suspected immigration offenders or refused passengers under the Immigration Act 1971.

There are strong safeguards in place. No clinical information about any individual is shared, and before any information at all is shared, there has to be a legal basis to do so. The MoU makes clear that NHSD retains the right to seek more information from HO should it need to and without limitation. NHSD may refuse a request for information from the HO if it is not satisfied that the request is in the public interest.

\textsuperscript{4} Using demographic data that the NHSD maintains in NHS databases, the tracing service responds to sanctioned tracing requests from a range of agencies and for a range of purposes. These purposes include traces for law enforcement teams, to find individuals who have been identified as potential bone marrow donors and to aid charities supporting people wanting to re-establish contact with family members.
Further detail is provided in Annex A to your questions. My officials are willing to discuss these further with you and other Health Committee members if that would be helpful. To arrange this, please contact DH’s policy lead Samantha Pryke at: Samantha.Pryke@dh.gsi.gov.uk.

I hope this is helpful and addresses your concerns.

Best wishes,

NICOLA BLACKWOOD
Annex A

Impact assessments
1. Was any impact assessment carried out before the memorandum of understanding was agreed? In particular, was (a) an equality impact assessment and (b) a privacy impact assessment carried out? If not, why were such assessments not carried out? If so, the committee would be grateful if you could supply copies of these assessments.

The potential impact of the arrangements described in the MoU were considered before it was agreed, in accordance with DH’s Public Sector Equality Duty (PSED) obligations and the Secretary of State’s (SofS) duty on health inequalities. As the MoU did not represent new policy development, but a confirmation of existing arrangements, impact assessments were not required purely for the establishment of the MoU.

However, DH did consider the potential impact of the arrangements described in the MoU with due regard to the PSED under section 149 of the Equality Act.

DH considered the potential impact of the continued data flow to trace immigrants on groups sharing a protected characteristic under the Equality Act 2010. DH was conscious of the legal requirement that the data sharing protocol must not unlawfully discriminate, or create barriers to advance equality of opportunity and foster good relations between those sharing protected characteristics and those who do not. DH worked with HO and NHSD to satisfy itself that there is a substantial public interest in sharing this non-clinical information to support effective immigration enforcement. The approach DH has taken to clarify the legal basis for these limited data exchanges has considered the impact on particular groups who could be affected by the protocol, such as vulnerable children and adults. DH satisfied itself that the agreed protocol was in compliance with the Equality Act 2010.

We consider that DH demonstrated due regard to Section 1 of the NHS Act 2006 (in particular the requirement for SofS to reduce health inequalities) through our work with Public Health England (PHE). This work explored the use of available and/or planned research to support better awareness and understanding of the impact of government policy on immigration enforcement on migrants’ health behaviours and their likelihood to seek treatment. We have found no evidence that this policy would deter migrants from seeking treatment. We are keeping this issue under close review, working with PHE, to consider whether further research needs to be commissioned by PHE within 2 years. We have agreed this as a recommendation in the NBO Review:

“PHE to undertake a review within two years to assess the impact on public health and health seeking behaviour arising from the disclosure of administrative data in relation to the investigation of criminal offences, including immigration offences.”

Privacy Impact Assessments (PIA) are a useful tool to identify, assess and mitigate the risks to privacy associated with new projects/initiatives. This initiative was not a new project but an existing data sharing activity. All data sharing activities, whether subject to formal PIAs or not, are subject to careful scrutiny and due diligence by policy and data sharing leads to ensure compliance with privacy and legal
obligations. For each HO request, NHSD carries out a public interest test to establish whether the information should be released (see para 7.8 - 7.12 of the MoU for further information). This test includes an assessment of the privacy implications and the competing public interest for and against the disclosure of the information to the HO. No clinical data (sensitive personal data) is requested or released under the MoU, and the information sought is considered to be at the lower end of the privacy spectrum. As a public interest test is carried out in each individual case, we did not carry out a PIA as it would not have provided any additional assurance in this instance. However privacy considerations were fully assessed as part of putting in place the MoU.

Consultation
2. What consultation was carried out with (a) clinicians, (b) patient representative groups and (c) groups protecting the rights of migrants before the memorandum was agreed?

We did not consult on the MoU because it was developed as an internal governance assurance document for existing processes between the HO, DH and NHSD.

However, the MoU is an outcome from the NBO Review and as part of the NBO Review there was engagement with representatives from bodies representing all of the groups above. The views expressed were embedded into the findings and recommendations of the NBO Review report.

Confidentiality
3. The Committee has been told that in the absence of a court order, the NHS does not share even the address of a patient with the police or any other public body, except in the most serious cases of harm to the person, involving murder, rape or manslaughter. Can you confirm that that is the case? What is the justification for adding immigration offences to the cases where confidential patient information may be shared?

It is not the case for demographic/administrative information that such information is shared solely for only ‘serious harm to the person’.

The data required and requested by the HO 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 and before any information at all is shared, there has to be a legal basis to do so. DH considers that such purely demographic/administrative information does not attract the duty of confidence, particularly when the information is capable of being extracted in its pure form from that health file.

As part of close work between DH, NHSD and HO to clarify the data flow, DH identified that the NHS Code of Confidentiality requires updating to re-correct an inaccurate presumption that the common law duty of confidentiality applies to demographic/administrative information which has evolved across the health sector.
The NHS Code of Confidentiality (the Code)\(^1\) sets out a narrow interpretation of a “serious offence” as akin to murder, rape, armed robbery and other offences of similar gravity. Having regard to the code NHSD does not, for example, include attempted murder as a “serious offence” – an offence punishable by life imprisonment. This is plainly an overly restrictive interpretation of what constitutes a “serious offence”. Section 261(5)(e) of the Health and Social Care Act (which provides a statutory basis for NHSD to share this information with the HO) allows for information to be disclosed where “the disclosure is made in connection with the investigation of a criminal offence (whether or not in the United Kingdom)”. There is no requirement under section 261(5)(e) that the offence must be “serious” in order to justify the sharing of information.

Whilst the Code remains out of date, DH recognises that there may be differences in approaches of health bodies in their treatment of similar administrative data, and whether such bodies regard such information as being subject to the common law duty of confidentiality. Notwithstanding the DH view that such information is not confidential, DH recognises that NHSD has chosen to treat this information as confidential and to apply the public interest test before making any disclosures.

The public interest in disclosing confidential information is not restricted to the consideration of only those offences noted as serious in the Code. The public interest test requires a detailed consideration of the privacy implications of the information to be disclosed against the public interest benefits in disclosure i.e. a balancing test. DH accepts that disclosure of confidential information must be weighed against a strong public interest in disclosure, but this is not limited to serious offences relating to serious harm against the person as listed in the Code alone.

DH plans to update the Code this year to provide a clearer definition in relation to what information is not to be classed or treated as confidential, and the definition of “serious offence”.

In relation to the justification for immigration offences, see the response to question 5 below.

**4. What assessment has been made of the compatibility of the arrangements set out in the memorandum with the General Medical Council guidance on the maintenance of confidentiality?**

As referred to above, DH’s position is that we do not consider this non-clinical information to attract the duty of confidentiality. Notwithstanding this, NHSD does treat administrative information as confidential and has considered its obligations in regard to the Code (as amended 2010) alongside statutory, judicial and common-law provisions.

NHSD carries out an assessment of the public interest and considers that the public interest is not limited only to assessment of harm to individuals, but can also take into account other benefits to society which can outweigh the individuals interest in

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keeping the information confidential, and that approach is not incompatible with the 
GMC guidance - see for example paragraph 37.  

In any event, recent authoritative 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. The general 
rule regarding health data is the more intimate and serious the type of information, 
the more onerous and prolonged is the obligation to maintain confidence. 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 the nature of the information in 
question being considered by the court to be “low on the spectrum of confidential 
information” (para 85). At para 34, the Court also stated, “The fact that the disclosure 
may be “less intrusive” than disclosure of detailed information about an individual’s 
medical condition and treatment does not mean that it is not intrusive at all or that 
the information is not inherently private. Instead, it means that it is likely to be easier 
to justify disclosure”. The DH view is that the HO requesting administrative 
information such as name, date of birth and address, falls into the less intrusive end 
of the spectrum.

5. What assessment has been made of the effect of the agreement of a 
memorandum on data-sharing between the Home Office and NHS Digital on 
wider patient perceptions of the confidentiality of patient data?

DH is committed to upholding public trust in data sharing and wider patient 
perceptions of the confidentiality of patient data. On that basis, DH considered the 
nature of the data requested by the HO and the public interest case for sharing it, by 
weighing up privacy considerations and the competing public interest in upholding 
the Government’s immigration agenda.

The importance of maintaining effective immigration controls is well recognised in 
Parliament, by the courts, and internationally. Effective immigration control is clearly 
in the public interest - and this interest extends to the power of government to 
remove, or prevent entry to, those individuals who might pose a danger to the public 
and who seek to abuse immigration laws.

As above, DH concluded that the data in question is administrative and can be 
extracted from a health file without attracting the duty of confidence. Nevertheless, 
even if it that was not considered be the case (and as noted above, NHSD treats the 
information as attracting the duty of confidence), we are fully confident that that the 
duty to maintain confidentiality of information at the lower end of the privacy 
spectrum would be overridden by the stronger public interest in supporting criminal 
enforcement and the Government’s clearly stated immigration agenda. We are 
satisfied that the public interest in disclosure clearly outweighs the duty of 

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2 The GMC guidance also states at section 37. “Personal information may, therefore, be disclosed in the public 
interest, without patients’ consent, and in exceptional cases where patients have withheld consent, if the 
benefits to an individual or to society of the disclosure outweigh both the public and the patient’s interest in 
keeping the information confidential. You must weigh the harms that are likely to arise from non-disclosure of 
information against the possible harm both to the patient, and to the overall trust between doctors and 
patients, arising from the release of that information.”
confidentiality (even if it applies to this category of administrative information) when considering:

- the administrative nature of the data in question;
- the HO’s need for the data in order to help locate individuals who are suspected of committing an immigration offence (under s24 or 24A of the Immigration Act 1971);
- the public interest test carried out by NHSD in relation to each HO tracing request, and;
- HO’s strict controls over who can access casework systems and the purposes for which they can access it.

The MoU formalises arrangements and clarifies the legal framework under which NHSD’s tracing services are provided to the HO. This publicly available document is open to scrutiny from all interested parties.

**Patient and public health**

6. What assessment has been made of the effect of the arrangements set out in the memorandum on the (a) likelihood of vulnerable people failing to access healthcare and (b) the cost to the NHS and the health impact on individuals if those fearful of the changes do not seek early treatment for serious health conditions as a result?

Medical treatment that is urgent or immediately necessary is never withheld irrespective of immigration status, so anyone in genuine need is able to receive treatment. Current NHS England policy is that primary care, including GP services, is accessible and free of charge to all, including short-term visitors and migrants, (whether illegal or otherwise).

By establishing a system for accessing NBO data in certain prescribed conditions, the HO is potentially able to bring suspected immigration offenders back into contact, to either regularise their stay or work towards their removal. We assessed that this is particularly important in respect of safeguarding responsibilities towards vulnerable children and adults who may be at risk, and public interest concerns regarding high harm individuals who are residing in the UK unlawfully.

Prior to agreeing the MoU, DH discussed this issue with PHE at length and concluded that, whilst there is a wealth of evidence about migrant health behaviours, there is no robust statistical evidence about the impact of knowledge of data sharing on deterring immigrants from accessing healthcare treatment. However, we accept that the MoU acts as a recent publication of an existing policy, which was not widely known beforehand. DH is therefore keeping this issue under close review, working with PHE to consider whether further research needs to be commissioned by PHE within two years. We have agreed this as a recommendation in the NBO Review:

“PHE to undertake a review within two years to assess the impact on public health and health seeking behaviour arising from the disclosure of administrative data in relation to the investigation of criminal offences, including immigration offences.”
7. What assessment has been made of the effect of the arrangements set out in the memorandum on public health—particularly with reference to the danger of the spread of communicable diseases as a result of patients not seeking treatment for fear of revealing their whereabouts to the immigration service?

See answer to question 6.

Public scrutiny
8. We understand that prior communications between NHS Digital and the Department of Health and groups concerned about the arrangements for data-sharing between NHS Digital and the Home Office has resulted in commitments from NHS Digital and the Department of Health that any formal agreement would be subject to proper scrutiny. How have those commitments been fulfilled?

The MoU represents the operationalisation of recommendations in the NBO Review. The NHSD NBO Review team worked with and engaged a wide range of stakeholders during the review process, and this thinking and the views expressed were embedded into the findings and recommendations of the report.

The groups engaged with represented patients, clinicians and groups protecting the rights of migrants and included:

Users:
- Charities
- Law enforcement bodies
- Local authorities
- Central government

Stakeholders:
- National Data Guardian
- Independent Information Governance Oversight Panel
- Public health representatives
- Civil liberties groups
- Immigration support groups
- Charitable health and care representatives
- Department of Health
- Clinical representative groups
Dear Sarah

Thank you for your letter of 2 March regarding the recently published memorandum of understanding (MOU) between the Department of Health, NHS Digital and the Home Office.

Public Health England (PHE) was not involved in this MOU, however we have had an opportunity to provide our advice on the potential public health impacts of sharing health records with immigration authorities through the NHS Digital National Back Office (NBO) review. We have recently confirmed our advice to the review (attached). Whilst there is a wealth of evidence about migrant health behaviours there is no robust statistical evidence about the impact of knowledge of data sharing on deterring immigrants from accessing healthcare treatment. Therefore, as a result DH have asked PHE to undertake a review of the evidence of its impact within two years.

Both I and PHE's Medical Director would be more than happy to meet with you to discuss any of the issues raised in our submission further.

With best wishes

Yours sincerely

Duncan Selbie
Chief Executive
1 Introduction

In 2014 the Health and Social Care Information Centre (HSCIC) published a report detailing the data released by their predecessor organisation, the NHS Information Centre (1). The publication of the report led to concerns being raised about certain aspects of the data released and a subsequent review of the HSCIC’s National Back Office (NBO) Tracing Team was initiated. Particular concerns have been raised about the impact of sharing demographic information with the UK Border Agency (UKBA), now Home Office Immigration Enforcement (HOIE), and police, to enable the tracing of individuals for immigration and border control purposes, on migrant’s access to healthcare. PHE’s response to the NBO review is outlined below.

2 Public health implications of NHS Digital sharing data with HOIE for immigration related offences

2.1 The view of experts working in the field of communicable diseases in PHE

PHE considers that sharing of personal information by NHS commissioners or healthcare providers, which has been provided to them by patients on an understanding of absolute confidentiality, with other government departments, law enforcement agencies or immigration enforcement authorities risks undermining public confidence in the public health system and could have unintended and serious consequences affecting the health of individuals and the risk to the public health of the wider community.

Effective communicable disease control requires easy and early access to clinical investigations, screening, diagnostic testing, treatment and preventative measures. Patients provide information to healthcare providers with explicit assurances about confidentiality and this is the basis for unfettered sharing of demographic and personal health data by patients with health systems; this has been the foundation of the public health system in the UK since the creation of the NHS. If patients have concerns that their personal information, even simple identifiers, could be shared with law enforcement or immigration enforcement agencies for the purposes of pursuing them for actual or alleged breaches of law or immigration rules, then this risks creating a real barrier to their engagement. Any barriers, actual or perceived, to patients accessing healthcare can have serious consequences. In particular this may impact upon asylum seekers, refugees and undocumented migrants or migrant groups legally in the UK who may be distrustful of sharing personal information for fear that it could be accessed by migration enforcement to locate them or their friends and family.

The public health importance of ensuring people are investigated and treated for infectious diseases is recognised in legislation and a list of communicable diseases where no charge is to be made is included in the National Health Service (Charges to Overseas Visitors) Regulations 2015 (2). In order for migrants to receive treatment for these conditions, access to services for clinical investigations, diagnosis, screening and testing must also be ensured.
Previous policy decisions have reflected the importance of ensuring migrants have access to healthcare for the detection and treatment of communicable diseases. For example, in 2012 a change to the overseas charging regulations was enacted so that HIV treatment was no longer chargeable. This decision was taken as a response ‘to the significant evidence on the benefits to public health of providing HIV treatment to all in clinical need’ (3).

2.2 Evidence that sharing data acts as a deterrent to migrants seeking healthcare

Despite difficulties in gathering data on access to care for undocumented migrants, evidence from the peer-reviewed and grey literature indicates that a fear of being reported to immigration authorities can act as a barrier to access internationally (4,5), in Europe (6–13) and in the UK specifically (14–17), even for migrants who are not undocumented (13) and those entitled to access healthcare (4). In the US, fear of disclosure to government officials has been shown to reduce or delay health seeking behaviour for several diseases including TB (4,18).

In the UK, a recent review of the migrant health literature identified a fear of deportation as a barrier to access (14). Community representatives for migrants in the UK reported confidentiality issues as one of the barriers to access for migrants, including fears about deportation (17). As a consequence of barriers to accessing healthcare, they reported that some migrants waited until their situation had worsened to access care and that late diagnosis had led to deaths in some cases (17).

A fear of deportation and use of ‘official services’ have also been specifically identified as barriers to accessing testing for communicable diseases in the UK (15,19) and other countries (11–13). For example, in 2016 the PHE TB Section received a query from a member of the public asking whether a person would risk being reported to immigration officials and deported if they presented to A&E with TB. Any perception that health care providers share information with HOIE could compound such problems and deter people from seeking healthcare. Although the proportion of migrants whose data are shared with HOIE may be relatively low, there could be a disproportionate impact on access to care arising from awareness among migrants that their data could be passed on. This could particularly affect the most vulnerable migrants, including victims of trafficking.

2.3 Migrants being deterred from accessing healthcare: impact on the individual

Although the majority of migrants are young and healthy, some bear a disproportionate burden of ill health. In the UK, the majority of the burden of communicable diseases falls upon particular groups of people who were born abroad (20,21).

Barriers to access can deter migrants from seeking appropriate healthcare in a timely manner, which can lead to long term health consequences for the individual both in terms of morbidity and mortality. For example, prompt HIV screening, diagnosis and treatment has been shown to reduce early mortality, morbidity and costly inpatient stays. In 2015, non-UK born heterosexuals were more likely to be diagnosed late with HIV in comparison to those born in the UK (21) and individuals diagnosed late with HIV have a ten-fold increased risk of death in the year following diagnosis in comparison to those diagnosed in a timely manner (22).
Migrants bear a disproportionate burden of tuberculosis (TB) and in 2015 almost three quarters of the TB cases notified in England were born abroad (23). For new migrants, the risk of developing TB is highest in the first few years after arrival [19,23,24], when fears of disclosure are likely to be highest and the consequences of delayed access to care are therefore greatest. Individuals with latent TB are at a particularly high risk of progressing to active disease in the first year after arrival (23). Early access to healthcare is therefore vital for screening and diagnosis of those with symptoms of TB, as late diagnosis has been shown to result in greater morbidity and mortality (24).

2.4 Migrants being deterred from accessing healthcare: wider public health risk

Ensuring access to healthcare for communicable diseases for migrants is not only required for the health of the individual, but for public health and communicable disease control more widely. For example, in the case of communicable diseases, such as TB or HIV, longer durations of undiagnosed disease increase the risk of transmission to others. The recent commencement of latent TB screening as part of the National TB Strategy depends in particular on migrants presenting for screening. The possibility that data may be shared directly counteracts national efforts to increase screening uptake upon which the effectiveness of the programme depends.

TB and HIV have been used as illustrative examples throughout this response, but barriers to accessing healthcare clearly have a significant impact on the early detection, clinical investigation, treatment, prevention and control of other communicable diseases (21) including STIs, vaccine preventable diseases and acute infectious diseases (e.g. influenza, SARS (25), MERS-CoV and Ebola).

Although access is clearly essential for those with symptoms, communicable disease control also relies on screening asymptomatic people at risk. Diseases such as HIV and chronic viral hepatitis can have very long asymptomatic phases during which transmission to others may occur. Screening to identify people who are infected can lead to treatment and behavioural modification which reduces the risk of infection or transmission of infection to others. National guidelines for a number of infectious diseases recommend screening asymptomatic at risk individuals for disease, and primary care practitioners play a crucial role in such screening. Barriers to migrants accessing care would therefore hinder this screening.

Potential public health consequences of impeded access to healthcare for migrants include a risk of increased transmission of:

- **TB**: TB is a major public health concern for England, and TB rates remain among the highest in Western Europe (26). Almost three quarters of the TB cases notified in the England in 2015 were born abroad (23) and so early detection, contact tracing and treatment is vital among migrants.

- **HIV**: In 2015, just over half of those newly diagnosed with HIV in England, where country of birth was known, were born abroad (22). Treatment reduces the amount of virus in the body to undetectable levels (27), which means the risk of passing on HIV infection is extremely low (28). Non-UK born heterosexuals are more likely to be diagnosed late with
HIV (42%, 882/1969 in 2015) and are therefore at greatest risk of developing AIDS and passing on their infection to others (21). Ensuring access to early diagnosis of HIV is therefore particularly pertinent for migrant populations at risk of HIV.

- **Viral hepatitis:** chronic hepatitis B disproportionately affects the non-UK born (20) and ethnic minority populations are more likely to be admitted to hospital or to die from severe liver disease as a result of hepatitis C (29). Effective treatments for hepatitis B and C are available, with some of the new hepatitis C drugs offering cure in the majority of infected patients. Undiagnosed and untreated hepatitis may be transmitted to others and therefore access to healthcare for early diagnosis is essential.

- **Acute infectious diseases:** pathogens such as influenza, SARS, MERS-CoV or Ebola can rapidly cause serious public health situations; the SARS epidemic in 2003 demonstrated how rapidly such infections may cross the planet (25). The outbreaks of Ebola in West Africa and MERS-CoV in the Middle East and South Korea underline the necessity of early detection and rapid communicable disease control and it is therefore vital that migrants are not deterred from accessing healthcare.

Communicable disease surveillance relies on the integrity of the underlying datasets to inform health protection, healthcare commissioning and disease prevention programmes. The sharing of data by HSCIC on request with HOIE may compromise the collection of this surveillance data, both by deterring patients from accessing services and discouraging healthcare providers from recording detailed information about their patients.

### 2.5 Migrants being deterred from accessing healthcare: economic consequences

Barriers to accessing healthcare in a timely manner can result in increased healthcare costs. For HIV the direct medical costs in the first year after diagnosis are twice as high for individuals diagnosed at a later stage with a CD4 count less than 350 cells/mm$^3$ (30,31). This increased cost is sustained as the costs of HIV care remain 50% higher in the years after diagnosis (30,31). For TB, barriers to completing treatment regimens increase the risk of the development of drug resistant disease (32) which is considerably more costly to treat (33).

Should delays in accessing care result in more hospitalisation and when people have no recourse to public funds for temporary accommodation, the risk of “bed blocking” rises increasing the costs to the NHS (34).

### 2.6 Impact on clinicians working with migrants and other populations

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 (35). This is a fundamental principle of working with patients which ensures public confidence and is enshrined in the General Medical Councils 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. While accepting the public interest argument for investigation of individuals for serious crimes (murder, manslaughter, sexual assault/rape etc.), most clinicians are unlikely to be aware that information about their patients could be shared for relatively minor issues like breach of immigration rules. There is a risk that once this becomes more widely known,
it may impact significantly on how doctors, nurses, pharmacists and a broad range of other allied health professionals engage with their patients and how they provide assurances about the potential use of demographic data collected by healthcare systems. The potential negative impact of this on personal and public health could be serious and may well deter people from seeking care.

3 Conclusions

In summary, it is the opinion of PHE that sharing demographic data from health records to facilitate the tracing of individuals in relation to possible immigration offences is concerning from a public health and personal healthcare perspective.

There is evidence that fear of deportation can have an effect on migrants in deterring access to healthcare. Anything which exacerbates existing mistrust among some migrants of health services and professionals (36,37) would compound other well documented barriers to access, including stigma (17) and a lack of understanding of the health system (16). A significant body of literature demonstrates the benefits of early detection and treatment of communicable diseases and it is therefore essential that migrants have timely access to healthcare.

PHE is the national expert agency for public health and responsible for fulfilling the Secretary of State (SoS) for Health’s statutory duty to protect and improve public health, and reduce health inequalities (under the Sections 2A and 2B of the NHS Act 2006, as inserted by the Health and Social Care Act 2012). PHE considers that the perceived or actual sharing of identifiable information from confidential health records in order to trace individuals in relation to possible immigration offences has the potential to increase the number of documented and undocumented migrants who either delay or do not seek medical treatment for a range of communicable diseases. It is the opinion of PHE that this could present a serious risk to public health and has the potential to adversely impact on the discharge by PHE of SoS’s statutory health protection duty.
4 References

1. Health and Social Care Information Centre. Review of data releases made by the NHS Information Centre.


15. Thomas F, Aggleton P, Anderson J. “If I cannot access services, then there is no reason for me to test”: the impacts of health service charges on HIV testing and


30. Health Protection Agency. Evidence and resources to commission expanded HIV testing in priority medical services in high prevalence areas. London; 2012.


06 March 2017

Dr Sarah Wollaston
Chair, Health Committee
House of Commons
London
SW1A 0AA

Dear Sarah,

Thank you for your letter of 27 February about the memorandum of understanding between the Home Office, NHS Digital and the Department of Health to enable the sharing of information to trace those suspected of immigration offences and your request for the GMC’s position.

We were not involved in the development of the memorandum. Like the Committee, we have however become aware of concerns from individual doctors and third sector organisations about patients who have no legal basis for being in the UK failing to register with a GP out of fear of immigration action.

Our confidentiality guidance for doctors emphasises the importance of trust in the doctor-patient relationship. Without it, patients may withhold information from their doctors, or even choose not to access health services at all. It is for these reasons that confidential medical care has long been recognised by the courts as being in the public interest, and our guidance reflects that.

We recognise that confidentiality is not absolute and that disclosures can be justified in the public interest, if the benefits to an individual or to society of the disclosure outweigh both the public and the patient’s interest in keeping the information confidential. But the existence of a confidential medical service is in itself a matter of public interest, and this must be taken into account in any balancing exercise that is undertaken to assess whether or not a disclosure is justified.

The memorandum of understanding sets out clearly the public interest in maintaining effective immigration controls. It does not however reflect the public interest in there being a confidential health system, or consider how those two public goods should be weighed against each other. We are therefore engaging with NHS Digital about how the memorandum will operate in practice. In particular,
I have written to its CEO, Andy Williams to seek assurances that they are giving appropriate consideration to the potential damage to public trust that could arise if it is perceived that patient data flows readily from the NHS to the immigration authorities.

With regard to your question about doctors’ responsibilities, our understanding is that the memorandum does not require doctors to do anything that they would not do otherwise or which would put them at risk of not following our guidance on confidentiality. Our concern would be how health bodies such as NHS Digital share this data about patients and whether they give appropriate weight to the public interest of a confidential medical service.

I hope this is helpful, do let me know if the Committee would like any further information.

Charlie Massey
13 April 2017

Dear Sarah,

Thank you very much for your letter of 28 March 2017. Please accept my apologies that my previous reply did not contain the level of detail you were hoping for, as our endeavour was always to provide the most fulsome response possible to assist the committee. I hope this letter provides you with all of the additional information you are seeking.

Firstly you asked if arrangements in the MoU mean that NHS Digital is now supplying the Home Office with exact addresses of individuals, rather than less detailed information based on postcode areas, and whether this represents a change from previous arrangements.

The MOU does not reflect a change in terms of the overall process followed by the NHS. It does, however, define changes in the way NHS Digital manages tracing requests from the Home Office, viz:

- NHS Digital will now supply to the Home Office an individual’s last known address using NHS registration data if the tracing request both meets the appropriate legal basis for disclosure and is assessed as being in the public interest.

- This represents a change to the information that we previously disclosed. It is not, however, a change to the information previously disclosed by the NHS system.

- The MOU does not represent a change in the legal basis for the release of data, the type of information released, the nature of the data or the source of the data. The information has always been extracted from an administrative source, such as the NHS Central Register (NHSCR).

In the past, when a trace request from the Home Office was approved, we gave the Home Office the address and contact details of the relevant Primary Care Support Service (PCS) organisation. The Home Office would normally then contact the PCS organisation and make a second data request for disclosure of the patient’s address details. (Note: PCS services are centrally provided by NHS England (NHSE). In September 2015 the service was renamed Primary Care Support Service England (PCSE)). DH advised us that on some
occasions and outside of this process, where the PCS organisation was unable to source this information, the HO may have contacted a GP directly for address details.

As described in the MOU, the process is now more streamlined; one request is made to NHS Digital; it is assessed in a standardised manner; and, should the request meet the legal requirements, only one release of information is required.

All of these process improvements were recommended by the Review as desirable and practical efficiency improvements which will ensure requests are handled consistently and which will reduce wider system burden and duplication of effort.

In a transparency sense the MOU also sets a new standard; both the number of tracing requests received and any subsequent approved releases of patient data are recorded by NHS Digital with volumes published periodically, as part of our routine data release register.

Secondly you asked for clarification about the extent to which the new process changes the opportunity for clinicians to intervene in the process.

I should take this opportunity to affirm that it has never been the case that, as part of this process, GPs or clinicians were ever contacted by NHS Digital or, as far as we know by PCS organisations, to secure their prior approval to release this information. There is therefore no material change to the GP’s opportunity to intervene in the way that you suggest.

- The information provided by NHS Digital has always been released from an administrative data source, for example the NHSCR, when there was an appropriate legal basis for this disclosure.
- NHSE have confirmed to us that the source of the data released by PCS organisations was NHS registration data, for which the local commissioning organisation were the data controller. The source of data used for tracing is now the NHS Central Register for which NHS Digital is data controller. In neither case were tracing requests referred to GPs or clinicians by the PCS or by NHS Digital.

The National Back Office Review concluded that NHS Digital does have a sound legal basis to release to the Home Office non-clinical information subject to consideration of public interests and after ensuring agreed safeguards are met.

Therefore under the new process, NHS Digital will undertake one assessment of the application and one public interest test on behalf of the system so that, assuming there is a valid legal basis to release the information, we will provide a total solution in meeting the Home Office request.

The streamlining advantages of the new proposal are clear; before the MOU was incepted, patient details were checked twice by two different organisations, with one releasing the NHS PCS locality and the other releasing the address information. In both cases the source data was the same (the NHSCR) and in both cases the application had to be fully assessed on its individual merits, with a public interest test being carried out by both the PCS and NHS Digital.
Your final questions concerned our consultation process and whether the arrangements set out in the MoU represent a material change from arrangements which previously pertained and whether the commitments we made were fulfilled.

The engagement approach adopted for the NBO Review mirrored the three-step methodology used for the preceding Partridge Review and other similar reviews; i.e. undertake analysis; consolidate and consider findings; and publish conclusions and recommendations for public consideration. The Terms of Reference for the NBO Review set out the process clearly;

- Identify and review the existing processes, controls and governance for each of the tracing activities.
- Assess compliance with prevailing control and governance arrangements.
- Identify and review the legal basis on which data is released for each of the tracing activities.
- Engage with and review user needs and requirements.
- Engage with the wider community of stakeholders to understand concerns and issues.
- Produce a report for the then HSCIC Board that describes the current service and provides recommendations of any changes to these services.

We set out with the aim of actively engaging with stakeholders and, where appropriate, the Review has sought to reflect several diverse perspectives. The conclusions are clearly documented in the forthcoming report which is due to be published shortly; - 'National Back Office Tracing Service - Review Findings'.

The Review did not at any point give a commitment or promise to formally consult with stakeholders prior to publication of its findings. We did commit to certain stakeholders that a copy of the report would be shared with them in advance of publication and this remains our intention as soon as the report is completed and its publication date agreed. We believe consultation post publication is the appropriate time for stakeholders to provide us with additional comments and feedback and we fully intend to do this. This approach is entirely consistent with the way that many reviews are conducted by several NHS ALBs.

In summary, the construct of the MOU seeks to address several structural issues;

- It addresses a weakness in the previous arrangements which were undocumented and not formalised. In the Report we highlight the need for a formal agreement to be put in place and we explain why we needed to tighten up procedures in this area.

- It makes it clear to the public and for all three signatory organisations, the exact legal basis, obligations, responsibilities and accountabilities of each party.

- It streamlines the existing process for obtaining information, reduces burden and sets a uniform standard for assessing the legal basis for accepting or denying the request. Furthermore, it does not materially or adversely change the intervention arrangements of GPs or any clinician involved in the patient's care compared to the situation ex ante.
• We have been keen to involve stakeholders in designing this next evolution of the Tracing Service and have worked with them throughout this process to guide and shape our thinking. We will continue to welcome feedback after publication when stakeholders will be able to see how their comments and feedback have shaped the development of the report and its findings.

In closing, I want to reassure you that we actively sought to engage widely and embrace diverse perspectives from various patient interest groups. This was part of a genuine and authentic willingness to consider all the issues, including those related to both patient privacy and to upholding our statutory obligations. We believe the MOU is a major step forward for the health and care system and for patients alike, which will become clear once the report is published.

Yours sincerely

Noel Gordon
Chairman
NHS Digital
Dear Sarah,

Thank you for your letter of 28 March 2017 which raised three further questions on behalf of the Health Select Committee following consideration of our response of 27 February 2017 about the Memorandum of Understanding (MoU) between the Home Office (HO), Department of Health (DH) and NHS Digital (NHSD) for locating individuals suspected of immigration offences.

The MoU sets out the administrative arrangements between the HO and NHSD in relation to tracing requests. It helpfully clarifies and confirms the purpose and legal basis of the exchange of non-clinical information between NHSD and the HO to locate those suspected of committing immigration offences, the procedural steps and responsibilities of the three signatory parties. We have formalised and refined an information exchange which has been ongoing for many years between the NHS and HO to ensure that it is proportionate and within an appropriate legal framework.

The first question seeks confirmation that the arrangements in the MoU mean that NHSD is now supplying the HO with exact addresses of individuals, rather than less detailed information based on postcode areas, and that this represents a change from arrangements which previously applied.

NHSD has confirmed that the previous information was not based on postcode areas but on Primary Care Support (PCS) area of registration. NHSD now supplies the HO an individual’s last known address using NHS registration data, if the tracing request meets the appropriate legal basis for disclosure, and is assessed as being in the public interest. This represents a change to the information NHSD previously disclosed but is not a change to the information previously disclosed by the NHS system. Previously, NHSD gave the HO the address and contact details of the relevant PCS organisation. The HO would then contact the PCS organisation and make a second data request for disclosure of the patients address details. The MoU therefore supports a clearer process with one request and release of information, enhancing
transparency and reducing wider system burden with less duplication of HO tracing requests.

We are aware that on some occasions, and outside of this process the HO may also contact a GP directly for address information – where the PCS organisation had been unable to source address information.

Secondly, you have asked for confirmation that the provision of the precise address via NHSD means that it is no longer necessary for the HO to seek permission from the individual’s clinician, that clinicians are therefore no longer able to assess whether they wish to refuse permission for that information to be passed to the HO before it is done, and that this also represents a change from the arrangements which had been in place previously.

It has never been the policy that clinicians were contacted by HO, NHSD or by PCS organisations to secure their approval to release this non-clinical information but occurrences may have happened as explained above. NHSD has always released the relevant PCS information, when there was an appropriate legal basis to do so. NHSE has confirmed that the source of data released by PCS organisations was NHS registration data, for which the local commissioning organisation was the data controller. The source of data used for tracing is now the NHSCR for which NHSD is data controller.

Finally you have asked about consultation with groups concerned about the MoU arrangements for data-sharing between NHSD and the HO and about why the promises of engagement with those groups as part of the National Back Office (NBO) Review, were not fulfilled in respect of the MoU. DH did not consult on the MoU as it is an internal governance assurance document between DH, HO and NHSD. Further, promises of engagement on the MoU could not realistically have been made as the MoU did not exist (nor plans for this) in August 2014. The MoU was developed in 2016 as a result of the NBO Review which identified the need for strengthened arrangements for processing HO requests for immigration purposes. NHSD engaged with a number of stakeholders on this work.

NICOLA BLACKWOOD
Letter via email

Dear Sarah

Re: NHS Digital’s National Back Office Review

Thank you for finding the time to speak to me about the Digital Economy Bill on 23 March, it was reassuring to know that we are reasonably aligned on the matter.

Thank you also for your correspondence of 28 March, in which you refer to the Memorandum of Understanding (MoU) between NHS Digital, the Home Office and the Department of Health concerning tracing requests for individuals suspected of immigration offences.

Representatives from NHS Digital came to a meeting of my advisory panel in late 2015 to discuss a number of points that they had surfaced during their review of the National Back Office (NBO) trace service. I am disappointed to say that they then failed to respond to some of the questions which we raised with them and did not re-engage with us until the recent press articles following the publication of the MoU with the Home Office and the Department of Health earlier this year.

We have now received a copy of NHS Digital’s draft review report and representatives from NHS Digital, the Department of Health and the Home Office met with some of my advisors and me on 6 March. On 20 March my panel of advisors and I discussed the MoU and the draft review report, which deals with a broader range of traces carried out by the NBO than those solely covered by the MoU. I have written to NHS Digital today to raise a number of concerns which I think should be addressed quickly.

I have attached a copy of my letter to NHS Digital, and do hope this is helpful to you and your committee colleagues during your further deliberations.

In your letter you also ask if I have any concerns regarding the principle of NHS Digital passing details of individuals to the Home Office in the way set out. My panel and I do have concerns about this, as any perception by the public that confidential data collected by the NHS is shared for a purpose that they had not anticipated or without appropriate controls may well lead to a loss of people’s trust.

You will know that I have highlighted the paramount importance of public trust in my recent report, and have long advocated a policy of ‘no surprises’ for the public about how data is used.

I believe that trust would have been better maintained had there been more public debate about where the balance should be struck between the public interest in maintaining an effective immigration service and the public interest in a confidential health service.
before an agreement was made between NHS Digital, the Home Office and the Department of Health. This would have allowed more scrutiny of the reasoning and factors which led to the policy position which has been taken.

I do welcome the scrutiny that you and your Parliamentary colleagues are giving to this matter and hope that this response has been of assistance. Please do let me know if a further discussion on any of these points would be helpful to you.

With best wishes

[Signature]

Dame Fiona Caldicott, MA FRCP FRCPsych
National Data Guardian
Letter via email

Dear Dean

Re: National Back Office Tracing Service

I am grateful to you and your colleagues at NHS Digital, the Department of Health and the Home Office for attending the National Data Guardian’s Steering Group meeting held on 6 March to discuss NHS Digital’s National Back Office (NBO) Tracing Service.

In addition to our considering the published Memorandum of Understanding (MoU) between NHS Digital, the Home Office and the Department of Health, it has been helpful to see the draft NBO Tracing Service Review Report, and I thank you for having shared this document with us prior to its publication.

Since the meeting on 6 March, I have also taken the opportunity to discuss these matters with the fuller membership of my advisory panel. Before I outline the key points that we would like to convey to you and colleagues who are copied into this letter, I must say that we were disappointed at the belated timing of the review’s re-engagement with us, following our previous discussions and the questions that we had posed to the review team in late 2015.

The key themes of the discussions that I have had with my panel have concerned transparency, the approach taken to tests of public interest, governance, and the potential impact on health seeking behaviour. These themes all speak to the issue of public trust, which you will know I highlighted in the review that I published last year, and in previous reviews and work.

I have outlined some of our concerns below and, where possible, have suggested some steps to address these. I must emphasise that they should be addressed as soon as is practicable so that the first annual renewal of the MoU, due by January 2018, can be appropriately informed.

The steps I have suggested are aimed at increasing the transparency of the releases made by the NBO and strengthening governance and oversight. Notwithstanding these suggestions, my panel members and I continue to have reservations about data which has been collected by the NHS, and is owed a duty of confidence, being used for the purposes of immigration control. We think that there has been insufficient discussion with the public about where the balance should be struck between the public interest in maintaining an effective immigration service and the public interest in a confidential health and care service.
Transparency
It is vital that people trust the health and care system to safeguard their data appropriately. Being as open as possible with the public about the circumstances under which data about them may be released is essential to the health and care system being seen as trustworthy.

I have long advocated a policy of ‘no surprises’ for the public about how their health and care data is used. Yet the publication of the MoU earlier this year came as a surprise to many. I do wonder whether this could have been reduced had there been more public debate before an agreement was made between NHS Digital, the Home Office and the Department of Health. This would have allowed more scrutiny of the rationale and factors contributing to the policy position which has been taken.

We believe that the publication of the review report will be an important next step in improving transparency about the releases of data made by NHS Digital’s tracing service. We would also encourage the publication of any further MoUs between NHS Digital and organisations receiving data through the tracing service.

We note that since July 2014, NHS Digital has issued quarterly publications of statistics about the numbers of trace requests received, accepted and made by the National Back Office in response to law enforcement. We would recommend that NHS Digital continues to provide these publications regularly, and also includes statistics related to the fuller range of releases made by the NBO - not just those made for law enforcement - to provide greater transparency still.

We note that NHS Digital has recently published, on its website, additional fair processing information for the public about the releases of data made by the NBO. We believe however that more should be done to help those registering for and using health and care services to be aware of the circumstances in which data about them may be released. We are not convinced that information placed on the NHS Digital website will be sufficient to achieve this aim. We therefore encourage the Department of Health and NHS Digital to consider how to improve the provision of information everywhere that people’s interaction with health and care services may result in their details being placed on the NHS Central Register, which is maintained by NHS Digital and used to carry out NBO traces.

Public interest tests
My panel and I are aware that the release of demographic data to law enforcement bodies to assist in the tracing of individuals suspected of criminal offences is just part of the work of the NBO. As the review acknowledges, the traces carried out in order to find individuals suspected of immigration offences have provoked the most discussion with the stakeholders you have engaged and this was also the area of most interest to us.

As you will be aware from our discussions, this was particularly due to the fact that when NHS Digital receives requests from the Home Office for assistance in tracing individuals suspected of immigration offences, the public interest test it applies to decide whether the data should be released does not take account of whether the alleged crime is serious. We noted that when NHS Digital applies public interest tests to trace requests from the police, the seriousness of the crime is considered. We further noted that both the NHS Code of Practice: Confidentiality 2003 and the General Medical Council’s (GMC) Guidance on Confidentiality (2009 and updated 2017) indicate that a public interest test may justify the disclosure of data held in confidence about an individual to protect individuals or society from serious crime.
We acknowledge that the type of demographic - not clinical - data released is considered to fall at the least intrusive end of the spectrum of medical information, following a Court of Appeal judgement referenced in the review report. We also understand that the legal gateways used for the release of these data (namely provisions under s.261 (5) of the Health and Social Care Act 2012) do not limit consideration of criminal offences only to “serious” crimes. You and your colleagues explained that the Home Office looks at other avenues to trace an individual before approaching NHS Digital. Further you made the point that by providing its tracing service, NHS Digital prevents these requests and the associated burden of meeting them flowing to frontline services. We also acknowledge the public interest in combating immigration crimes.

However, we do believe that where a public interest test is applied to these releases, the differences between the approaches to such tests taken by NHS Digital and the approaches described in the NHS Code of Practice and the GMC guidance merit further clarification. We note that the Department of Health has agreed the need to review the NHS Code of Practice: Confidentiality 2003. Given the importance of this matter, we consider this to be urgent and would expect the work to be carried out in consultation with the relevant bodies, including the General Medical Council, Nursing and Midwifery Council, Health and Care Professions Council and others.

We understand that NHS Digital’s position is that due to the GMC guidelines it is not appropriate for doctors at NHS Digital to be involved in individual public interest tests in relation to traces for immigration purposes. Nonetheless, we believe a clinical perspective remains essential in order for NHS Digital to ensure that the framework in which public interest tests are made properly weights the public interest in maintaining medical confidentiality.

**Governance**

My panel members and I would have liked to have seen more detail in the review report about the governance and oversight of the NBO Tracing Service. We also think it will be important for there to be clear and transparent governance processes and independent oversight around the MoU between NHS Digital, the Home Office and the Department of Health, and any subsequent MoUs.

We recommend that NHS Digital conducts an internal audit, checking on adherence to the public interest test, balancing the public interest in medical confidentiality against the public interest in the combating of immigration offences. We believe that this audit should be followed by an external audit. There should be an element of independent oversight to both the internal and external audits, which might be provided for example by NHS Digital Non-Executive Directors, the Independent Group Advising on the Release of Data. It may well build confidence if the results of audits are published alongside more detail than the review report currently provides of the way that the public interest tests balance the factors at play.

We suggest that the internal audit should be undertaken as part of a review of the MoU between NHS Digital, the Home Office and the Department of Health before its planned annual renewal, which we understand is due by 1 January 2018.

Also as part of that review, we recommend that the MoU and any subsequent MoUs are subject to appropriate governance processes at NHS Digital and to independent oversight, including review by the NHS Digital Board.

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1 Court of Appeal judgement W, X, Y and Z v Secretary of State for Health, Secretary of State for the Home Department and British Medical Association [2015] EWCA Civ 1034, in regard to the 2014 High Court decision - R (On the Application Of W & Ors,) v Secretary of State for the Home Department [2014] EWHC 1532 (Admin).
Potential impact on health seeking behaviour
When you and your colleagues attended our Steering Group meeting on 6 March, we discussed the potential for these releases of data to deter some vulnerable individuals from seeking healthcare for fear that details they provide to health and care services would later be provided to immigration officials.

We acknowledge that the review stated the evidence it found of this occurring was anecdotal and insufficient to justify suspending or changing trace services. However, we also note that organisations such as Doctors of the World and the National Aids Trust have argued that the deterrent effect is real and observable and that the need for research to be initiated was raised with the NBO review team by myself and my panel in 2015.

We see that the review recommends that Public Health England (PHE) should undertake a review within two years of the impact on public health and health seeking behaviour arising from the disclosure of administrative data, in relation to the investigation of criminal offences, including immigration offences.

Given the importance of this matter, we would encourage the Department of Health to commission PHE to start this research as a matter of urgency. We accept that it may not be possible for this work to be concluded before a first annual review of the MoU. However we hope that it may be possible for early findings to be taken into account at this point.

I have received a letter from Dr Sarah Wollaston MP in her capacity as Chair of the House of Commons’ Health Select Committee asking my views on the MoU. I will therefore be sharing a copy of this letter with Dr Wollaston and her committee.

I hope that this response is helpful to you. Please do contact my office if you require clarification on any of the matters in this letter. I would be grateful if you would keep in touch with my panel and me as you prepare to publish the review. It would also be very helpful to hear from you, or the responsible member of staff at NHS Digital, as you prepare to undertake the first annual review of the MoU to understand what activities will form part of that process, and whether any advice from my panel and me might be helpful at that point.

Yours sincerely

Dame Fiona Caldicott, MA FRCP FRCPsych
National Data Guardian

CC

Sir Ian Andrews, Non-executive Director, NHS Digital
Katie Farrington, Department of Health
Sam Pryke, Department of Health
Tim Rymer, Home Office
Professor Martin Severs, NHS Digital
Steve Smith, NHS Digital
Hazel Randall, NHS Digital