Royal College of Midwives submission to National Data Guardian consultation about priorities

March 2019

The Royal College of Midwives (RCM) is the trade union and professional organisation that represents the vast majority of practising midwives in the UK. It is the only such organisation run by midwives for midwives. The RCM is the voice of midwifery, providing excellence in representation, professional leadership, education and influence for and on behalf of midwives. We actively support and campaign for improvements to maternity services and provide professional leadership for one of the most established clinical disciplines.

We welcome the opportunity to respond to the National Data Guardian's draft priorities. We have comments to make on Priority 4: *Safeguarding a confidential health and care system*

Q10. Should Safeguarding a confidential health and care system be one of the NDG's top priorities?

Yes

Q11. Are the outlined areas of NDG interest the right ones for the NDG under this priority? Please tell us if there are other areas we should be looking at under this theme, or if you think others would be better placed to do the work

The RCM, along with many other professional organisations representing members working the NHS, have serious concerns with elements of the 'hostile environment' created in recent years in England, of which sharing migrants' health data for immigration purposes is a part.

The RCM believes that all pregnant women and new mums need timely access to maternity care, without restrictions, to safeguard maternal and neonatal health. Our reasons for this are based on the clear evidence from confidential inquiries into maternal death and research into health inequalities in maternal and neonatal outcomes, where access is a critical component to outcomes. Further, the latest report into maternal death in the UK finds 'the risk of maternal death in 2014-16 is yet again significantly almost five-fold higher among women from black ethnic minority backgrounds compared with white women.'[1] Health inequalities for vulnerable people must be part of any context in which data sharing risks are considered. Maternity care is deemed immediately necessary in the Cost Recover Programme, meaning women who are charged for their NHS maternity care should never have that care withheld or delayed cause of lack of payment.

You will be well aware of the controversy around the Memorandum of Understanding between NHS Digital and the Home Office. The regulations around Cost Recovery allow for information sharing

[1] Knight et. al (2018). 'Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2014–16'. MBRRACE-UK, Maternal, Newborn and Infant Clinical Outcome Review Programme. Oxford. https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202018%20-%20Web%20Version.pdf

between the NHS and the Home Office for immigration purposes. Moreover, those who have debts of £500 or more outstanding for NHS care for more than two months have this information passed to the Home Office. This affects their visa applications to regularise their status in the UK. Research by Maternity Action into women charged for maternity care finds that many of those charged for NHS maternity care have no access to sensible repayment plans and are destitute. They turn away from maternity care to avoid debts they cannot not pay.[2]

Midwives' ability to care for women is dependent on trust and we agree with and welcome your statement that 'People using health and care services must feel able to discuss sensitive matters with a doctor, nurse, social worker or other member of their care team knowing that information they have provided will not be improperly disclosed.'

In recent years, midwives working in the NHS have been asked by the government to identify, and refer on, women who are victims (or at risk of) of FGM,[3] homelessness,[4] domestic abuse,[5] and, currently under consultation, forced marriage.[6] Midwives are entrusted with these duties because of the recognition that they reach the hard-to-reach more than other professionals and that they may be the only person a woman can trust. Anything that damages trust between women and midwives, and hinders women's access to care, damages these laudable initiatives to identify and refer women at risk. It also damages the Secretary of State's ambition to make England the safest place in the world to have a baby. The RCM believes the hostile environment is not the safest place to have a baby. We have campaigned against charges for NHS maternity care for many years, and we have opposed the routine data sharing between the NHS and the Home Office which treats migrants data with less care than others'; we think this is discriminatory and hugely risky.

Recent research by the Equality and Human Rights Commission showed NHS migrant charging and data-sharing policies prevent and deter people seeking asylum from accessing healthcare services.[7] Public Health England warned sharing patient data for immigration purposes '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.'[8] We support the view of the Health and Social Care Committee, which called for the suspension of the data sharing MOU until sufficient safeguards could be put in place to protect access to the NHS.[9]

12. What would you like to see the NDG do in this area?

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[2] Rayah Feldman (2018). What Price Safe Motherhood? Charging for NHS Maternity Care in England and its Impact on Migrant Women. Maternity Action, London. https://www.maternityaction.org.uk/wp-content/uploads/WhatPriceSafeMotherhoodFINAL.October.pdf

[3] Department for Education and Home Office (2015). Mandatory reporting of female genital mutilation: procedural information. https://www.gov.uk/government/publications/mandatory-reporting-of-female-genital-mutilation-procedural-information

[4] Ministry of Housing, Communities and Local Government (2018). Homelessness: duty to refer. https://www.gov.uk/government/publications/homelessness-duty-to-refer

[5] Cabinet Office (2018). Anonymous voter registration made easier for domestic abuse survivors. https://www.gov.uk/government/news/survivors-of-domestic-abuse-now-able-to-vote-anonymously

[6] Home Office (2019). Preventing and tackling forced marriage: a consultation. https://www.gov.uk/government/consultations/preventing-and-tackling-forced-marriage

[7] Equality and Human Rights Commission (2018). The lived experiences of access to healthcare for people seeking and refused asylum. https://www.gov.uk/government/news/survivors-of-domestic-abuse-now-able-to-vote-anonymously

[8] Public Health England (2017). Letter to Health Select Committee, available in 'Correspondence regarding Memorandum of Understanding (MoU) between NHS Digital, the Home Office and the Department of Health on data sharing. https://www.parliament.uk/documents/commons-committees/Health/Correspondence/2016-17/Correspondence-Memorandum-Understanding-NHS-Digital-Home-Office-Department-Health-data-sharing.pdf

[9] Health and Social Care Select Committee (2018). 'Memorandum of understanding on data-sharing between NHS Digital and the Home Office: Fifth Report of Session 2017–19'. https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/677/677.pdf

We understand from the letter from Sarah Wollaston MP to NHS Digital, following her Committee's evidence session with NHSD, that the routine sharing of migrants' data outlined in the MOU was not subject to the usual governance and consultation processes – including with yourself – around patient medial records and confidentiality:

> '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). 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.'[10]

It is for these reasons that we urge the Data Guardian to consider migrants' data, and more specifically, the transfer of NHS health data to outside agencies for immigration purposes, as matters of priority. The findings of the Health and Social Care Committee on the MOU, and the now significantly delayed publication of PHE's review into the impact of data sharing on health seeking behaviour, shows that this issue has not been resolved. The NDG is perfectly placed, with its statutory footing and wide-ranging scope, to hold NHS Digital, the Home Office and the Department of Health and Social Care to account for their policies which damage the faith the public can have in the NHS, and between midwives and women.

[10] Sarah Wollaston MP, Chair, Health and Social Care Committee, letter to Sarah Wilkinson, Chief Executive, NHS Digital. 29 January 2018.