

Nursing and Midwifery Council response to the National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-outs consultation

Introduction

- 1 The Nursing and Midwifery Council (NMC) is the professional regulator for nurses and midwives in the UK. We exist to protect the public. We do this by holding and controlling access to the register of qualified nurses and midwives and setting standards of education, training, conduct and performance. If an allegation is made that a registered nurse or midwife is not fit to practise, we also have a duty to investigate and, where necessary, take action to protect the public.

Our response

- 2 We welcome the opportunity to respond to the proposals outlined in this consultation. We are pleased that the Government is acting on the recommendation in Dame Fiona Caldicott's review to hold a public consultation on these proposals. Below we have provided our comments on some of the specific consultation questions which we feel are most closely relevant to our remit as a professional regulator.

Question 4: The Review proposes ten data security standards relating to Leadership, People, Processes and Technology. Please provide your views about these standards.

- 3 The core professional standards expected of all nurses and midwives are set out in our Code¹. This covers fundamental aspects of a nurse and midwife's role, including information sharing. Registered nurses and midwives are under professional duties to protect patients' information from improper disclosure. There is a strong interface between the 'people' cluster of the proposed standards and the responsibilities registered nurses and midwives have under our Code, particularly those relating to respecting people's confidentiality and sharing information appropriately.
- 4 Our Code makes it clear that we expect registered nurses and midwives to make sure that people are informed about how and why information is used and shared by those who will be providing care. The 'people' cluster will help ensure that nurses and midwives have the right tools, training and support to meet their responsibilities for handling and sharing data safely. This will in turn help them comply with the relevant professional standards they must follow.

¹ NMC (2015), The Code – Professional standards of practice and behaviour for nurses and midwives, <https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf>

Question 10: Do you agree with the approaches to objective assurance that we have outlined in paragraphs 2.8 and 2.9 of this document?

- 5 We see merit in ensuring that the Care Quality Commission (CQC) embeds the proposed standards in its inspection approach, as proposed in the consultation. This will provide assurance of compliance against the new data security standards and ensure that they are consistently implemented by organisations across the health and care system.

Question 11: Do you have any comments or points of clarification about any of the eight elements of the model described above? If so please provide details in the space below, making it clear which of the elements you are referring to.

- 6 We understand that the proposed new eight point opt-out model has been designed to provide a simpler and less complex approach in terms of how people's personal confidential information will be shared for purposes beyond their direct care. However it must be acknowledged that the current system provides two different layers of opting out: objecting to information being shared outside a GP practice for purposes other than direct care (type 1) and objecting to information being shared outside HSCIC (soon to be NHS Digital) for purposes beyond the individual's direct care (type 2). The proposed model will change the flow of personal confidential data by allowing all data to flow into the HSCIC. The implications of moving away from individuals having more than one choice must be carefully considered and the reasons of those who do opt out better understood.
- 7 We strongly agree that data sharing is needed to ensure safe and effective care, while at the same time protecting confidentiality.
- 8 While there is value in articulating the proposed new model through simple, concise statements, we believe this should not come at the expense of clarity. In particular, further detail to expand on the concept of 'direct care' would be beneficial. It would be helpful to explicitly state whether this only covers information shared within the healthcare team or whether it extends to information shared with individuals who are not health professionals but may support the provision of direct care. For example, the administrative and clerical support which help healthcare team to work effectively. In addition, it would be welcome to clarify that the concept of 'direct care' is not confined to only professionals who have direct contact with the patient. This would ensure that the parameters of the proposed opt-out model are clearly understood and there is no potential for confusion.
- 9 We would welcome further clarity that the proposed model is intended to only capture individuals' right to opt-out from their personal confidential being used for purposes beyond their direct care. The right to opt-out captured in the fourth statement is limited to uses of information for purposes other than direct care, while the second statement acknowledges that an individual can object to the disclosure of personal information by those who are providing their care but does

not explicitly refer to this as being an opt-out which may cause some confusion. We understand that the proposed model will not change the current system with regard to sharing for direct care and are aware that the Department of Health issued in 2014 guidance for health and care professionals on 'Confidentiality and Information Sharing for Direct Care'². This sets out clear rules for information sharing as part of a person's direct care and may be helpful to link to.

- 10 We support the proposed exemptions to the opt-out model. We are pleased that investigations carried out by professional regulators will not be caught by the opt-out. This is consistent with provisions in the Nursing and Midwifery Order 2001³ which give the NMC powers to require disclosure of patient information for the purpose of discharging our statutory function in relation to fitness to practise.
- 11 We support the proposed exemption to the opt-out where there is a legal requirement to share information. We also welcome the exemption that touches on the obligation on professionals to share information for child or vulnerable adult safeguarding purposes. This mirrors the provisions of our Code which states that registered nurses and midwives must share information if they 'believe someone may be at risk of harm, in line with the laws relating to the disclosure of information'. Likewise, we welcome the recognition of areas where health professionals including nurses and midwives are subject to more specific duties such as in relation to FGM.

Question 12: Do you support the recommendation that the Government should introduce stronger sanctions, including criminal penalties in the case of deliberate or negligent re-identification, to protect an individual's anonymised data?

- 12 Where a nurse or midwife may not have acted in accordance with professional standards, our fitness to practise process enables us to take action in order to protect the public. The purpose of any action we take is to protect the public by helping to make sure nurses and midwives on our register provide safe care and to uphold public confidence. The outcome of our fitness to practise process can be to suspend the nurse or midwife's right to practise, or to restrict their practice – for example by requiring them to work under supervision. Nurses and midwives must work within the Code and other national standards, including in relation to information sharing. In cases of serious breaches, a nurse or midwife may be removed from our register and prevented from practising.

² Department of Health (2014), *Confidentiality and Information Sharing for Direct Care - Guidance for health and care professionals*

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/371932/OE_010079_IGA_Staff_Leaflet_A4_Lanv7_A-W_Final_Single_pg-Web.pdf

³ Article 25 of the Nursing and Midwifery Order 2001,

<https://www.nmc.org.uk/globalassets/sitedocuments/legislation/legislation-updated/the-nursing-and-midwifery-order-2001-consolidated-text-effective-from-2016.01.18.pdf>

- 13 Should the Government see the need for a new criminal offence for deliberate or negligent re-identification of data, this is within the Government's purview to introduce. Criminal sanctions would represent an additional tier on top of existing sanctions, including sanctions that professional regulators can impose. We believe this should only be considered if evidence can be produced that sanctions currently in place have proved insufficient. We do not believe the consultation adequately makes the case for the need to create additional sanctions.
- 14 The introduction of a new criminal offence would have implications for the NMC as a statutory regulator. If a registered nurse or midwife is subject to criminal proceedings for deliberate or negligent re-identification of data, then questions will also be raised about their fitness to practise and we would expect them to be referred to the NMC. We acknowledge that one potential benefit arising from the introduction of this offence is that, in the event of a criminal conviction, the level of investigation required within our Fitness to Practise (FtP) directorate would be reduced, meaning that the FtP case could be dealt with quicker and with less resource.
- 15 However it is imperative to be aware that criminal proceedings and action by a professional regulator fulfill different objectives. The outcome of a criminal investigation may not satisfy the wider need for public protection so regulatory action may still be needed. We do have some concerns about the impact on our proceedings caused by cases which may be captured by a new offence. Where a criminal investigation has concluded that a nurse or midwife is not guilty of a criminal offence, this does not necessarily mean that there will not be other professional issues raised in relation to the nurse or midwife, which we will need to investigate. We consider that there may be significant delay on our proceedings due to the amount of time required by the authorities to investigate these cases and take a decision on whether to prosecute. It should be noted that such delays may well have an impact on patient safety.
- 16 The consultation does not contain details on the scope or design of any such criminal offence. However, if criminal sanctions are deemed appropriate, we would wish to be closely involved given the link across with our fitness to practise proceedings.