Royal College of Nursing
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Response to

National Data Guardian for Health & Care's Review of Data Security, Consent & Opt-Outs Consultation

Background

The RCN participated in the review on which this consultation is based and has signed up in principle to its key proposals.

General comments

We welcome the recommendations and see them in total as being a good way of providing and promoting good practice in data handling across the health and care system in England.

However, we feel that there is a danger that they may be perceived negatively by health and care staff if they are not implemented and enforced in a positive manner, and would recommend that their introduction be undertaken with care.

In promoting and disseminating these new arrangements health and care staff will need to be reassured of their responsibility to continue making statutory disclosures even if no consent is secured or possible, for instance in relation to safeguarding children and /or vulnerable adults.

Lastly, the reference to 'consent and opt-outs' is potentially confusing, and we recommend rephrasing as 'consent, withholding consent and opting-out', to ensure clarity for both those using, and those subject, to the new arrangements.

Responses to Key Consultation Questions

Q3: If the Department of Health or other organisations were to create further opportunities to engage on data security and the consent/opt-out model, would you be interested in attending? If so where would you find it helpful an event to be held?

This is an excellent idea, and we suggest a regional programme of events, supported by a simple and clear communications strategy, to ensure that all health and care workers are apprised and supported in their responsibilities and obligations when handling personal confidential data.

It would also be helpful to have presentations from the General Medical Council (GMC) and the Nursing and Midwifery Council (NMC) at these events, to highlight how the recommendations sit alongside the responsibilities that regulated healthcare staff have under their respective codes.

Q4: The Review proposes ten data security standards relating to Leadership, People, Processes and Technology. Please provide your views about these standards.

We welcome the standards, and specifically the clear approach they give to the use and management of personal confidential data.

Q6: By reference to each of the proposed standards, please can you identify any specific or general barriers to implementation of the proposed standards?

Standard 3: Annual training and Mandatory Test.

We welcome to intention of this requirement, but feel that more detailed information needs to be provided to ensure a consistent and robust approach is taken across the health and care system; especially in relation to smaller and independent providers.

We are concerned about the potential for this to become a 'tick-box' exercise, and recommend more consideration be given in planning for implementation as to how learning can be incorporated into the process on an on-going basis, for example by referencing high-profile data breaches and sharing examples of good practice.

There are a number of key issues that we feel will need to be addressed in the Department's response to this consultation, specifically:

- What will happen if a health or care organisation's staff are not able, for whatever reason, to meet the proposed training requirements; for example will they be prohibited from handling patient data until they have met the requirements?
- Will there be any sanctions for organisations that do not enforce the training requirements, and if not is there any consideration for how such non-compliance will be addressed?

- Is there any expectation for the training and assessment proposals to align with the revalidation processes now in operation for medical and nursing professionals?

We feel that these are important issues that need to be addressed to ensure that the proposals do not end-up as merely a tick-box exercise that has no impact on organisational or sector behaviours in the way patient data is handled.

Q7: Please describe any particular challenges that organisations which provide social care or other services might face in implementing the ten standards.

The biggest challenge will be to ensure equity and consistency in training and implementation across the social care and independent sectors, and to ensure that data systems are interoperable.

Small health and care providers might be financially challenged by some of the requirements, for instance the annual training and test requirement, as we know that many staff working in these providers already have difficulty accessing training. On that basis it may be helpful to examine the viability of using 'e-Learning for Healthcare' to support on-going training and development, to improve ease of access for professionals in these environments.

Q 9: What support from the Department of Health, the Health & Social Care Information Centre, or NHS England would you find helpful in implementing the ten standards?

We recommend a national information campaign be undertaken, to inform staff and the general public of the standards, and of their rights and obligations.

We would also recommend that a dedicated funding stream be established to support transition to the new arrangements, and given sufficient money and longevity that the changes can be demonstrably embedded and working in practice.

Lastly we recommend that a review be undertaken of how the arrangements are bedding in, which can both identify good practice and highlight where there is need for further work, ideally after not less than one year after implementation.

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

We support the proposal for the Care Quality Commission to amend its inspection framework to take account of the new standards.

We agree with the analysis regarding primary care, and support the proposal for NHS Digital to provide additional support to any organisations that need it. We recommend consideration also be given to offering this to social care providers (including independent and third-sector), such as care homes, residential children's homes, hospices, and domiciliary care providers.

Q11: Do you have any comments or points of clarification about any of the eight elements of the model described above?

The reference to 'consent and opt-outs' is confusing. We recommend rephrasing to 'consent, withholding consent and opting out', to ensure clarity for both those using, and those subject, to the new arrangements.

Q12: Do you support the recommendation that the Government should introduce stronger sanctions, including criminal penalties in the case of deliberate re-identification, to protect an individual's anonymised data?

We support this proposal. All registered nurses are also governed by the NMC Code (2015), which contains obligations regarding the use and management of data, and would be used in the first instance to sanction any alleged misconduct relating to the improper handling of confidential data by any registered nurse (Sections 5 and 10).

Q15: What are your views about how the transition from the existing objection regime to the new model can be achieved?

We recommend a plan of action be established at the national (England) level, with consideration given to what resources and training will be needed to ensure an effective transition.

This should fully embrace the role that health and care staff need to play in communicating to patients the issues and practicalities that underpin the use and management of personal health data, and this should include those staff that support patient groups, or undertake patient participation work.

Q 16: Do you think any of the proposals set out in this consultation document could have equality impacts for affected persons who share a protected characteristic, [as described above]?

We have no specific concerns at the moment regarding the proposal's impact on persons sharing a protected characteristic, but would strongly recommend that robust monitoring

and evaluation mechanisms are put in place during their implementation, and especially in the transition to the new consent arrangements.

These mechanisms must include feedback opportunities for frontline health and care staff, to ensure that any developing impacts are picked up as early as possible, and can then be addressed as quickly as possible.

Q 17: Do you have any views on the proposals in relation to the Secretary of State for Health's duty in relation to reducing health inequalities?

We believe it is vital that the proposals as laid out do not undermine the Secretary's Health Inequality Duty, and recommend that the outputs of the active monitoring (as described in response to Q.17) are used to pro-actively inform Ministers and relevant government departments of any problems or complications being created by the new arrangements. This should include targeted monitoring and reporting for, at a minimum, individuals with protected characteristics.

About the RCN

With a membership of around 435,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector.

We promote patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

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