

Royal College of Nursing Response to the National Data Guardian's consultation about revising, expanding and upholding the Caldicott Principles

The RCN welcomes this timely consultation. We recognise the great value that the use of patient's confidential information has in improving patient care, public health interventions and health research. We also believe that patients are more likely to share confidential information when there is clarity and transparency as to how their data is used, by whom and for what purpose. This consultation is a step in the right direction for enhanced transparency and public engagement; both needed to guarantee that the balance between health data sharing and the individuals' right to privacy.

Consultation item 1 - Views on the proposed revisions to the seven existing Caldicott Principles

The RCN recognises the need for "clear guidance, greater simplicity to support clear and confident decision making around the use and sharing of data and clarity for the public" and believes that the proposed new wording does meet this objective for the seven existing principles.

The RCN welcomes the fact that the new wording has clarified that the safeguarding principles apply to all the patients' 'confidential information' instead of only to their 'personal information.' By doing so, the National Data Guardian (NDG) has extended the individuals' control over their data to include a wide range of information, not all of which is considered personal information.

Consultation item 2 - Views on the 'proposed extension of the Caldicott Principles through the introduction of an additional principle (Principle 8)

The RCN believes that the headline of the additional principle could be worded so that it reads more clearly. Therefore, we propose replacing the original wording ('Principle 8 - Inform the expectations of patients and service users about how their confidential information is to be used) with the following more precise and direct wording:

'Principle 8 - Patients and service users expect to know the uses of their confidential information'.

The proposed wording would logically align with the statement that follows:

'A range of steps should be taken to ensure 'no surprises' for patients and service users about how their confidential information is to be used - these steps will vary depending on the use. As a minimum, this should include providing relevant and

appropriate information - in some cases, greater engagement will be required to promote understanding and acceptance of uses of information. Patients and service users should be given an accessible way to opt-out'.

Consultation item 3 - Views on the 'NDG using their statutory power to issue guidance about organisations appointing Caldicott Guardians to uphold the Caldicott Principles'

The RCN believes that upholding the Caldicott principles requires high-quality guidance that is regularly reviewed to keep pace with and anticipate technological change, so those individuals who oversee the use and sharing of patients' confidential information in each organisation have the necessary information to balance data sharing in the public interest and the individuals' right to privacy.

We believe this guidance should highlight the role that organisations and Caldicott Guardians play in protecting patients' confidential information from the risks attached to the use of new technologies, such as digital apps used by the NHS to collect patient data. The digitalisation of health data has revolutionised how healthcare information is shared by individuals and handled by all third-party actors in the public or private sectors. As a result, we believe the future guidance should equip Caldicott Guardians with the knowledge needed to identify the risks to personal data breaches and implement technical solutions to prevent cyber-security attacks.

The guidance should also highlight the role of organisations and the Caldicott Guardians themselves in supporting patients to develop the 'digital literacy' needed to understand how and when to opt-out of sharing their confidential data. They also must take the necessary steps to clarify to patients when the sharing and use of their confidential data without their consent is justifiable.

Finally, we expect the outcome of this consultation to be an improved data governance framework that protects the individuals' right to control their data while facilitates the ethical use of patient's confidential information.

About the Royal College of Nursing

With a membership of around 450,000 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. The RCN promotes 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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