

Response ID ANON-JE4C-RYJA-V

Submitted to **Caldicott Principles: a consultation about revising, expanding and upholding the principles**
Submitted on **2020-09-02 16:38:22**

About you

1 In what capacity are you responding to this consultation?

On behalf of an organisation

Other:

2 If applicable, please provide the name of your organisation:

Organisation:

General Medical Council

3 If applicable, please tell us what type of organisation you work for - please tick all that apply:

Other – please specify below

Other:

Professional regulator

4 If applicable, please tell us what your role is - please tick all that apply:

Other – please specify below

Other:

Policy Officer

Revising and expanding the Caldicott Principles

5 Do you agree that the NDG should introduce the new proposed principle (number 8 in the list above)?

Strongly agree

If you think it would be useful for us to know why, or if you have specific amendments to suggest, please use the free text box to tell us.:

We strongly support the addition of this principle that there are 'no surprises' for patients and service users about how their confidential information is to be used. This is closely aligned with the main principles in our guidance, Confidentiality: good practice in handling patient information. This includes the relevant expectations that doctors should:

- tell patients about disclosures of personal information they make that patients would not reasonably expect; and
- respect, and help patients exercise, their legal rights to be informed about how their information will be used and to have access to, or copies of, their health records.

In our guidance (paragraph 29), we say that if doctors suspect a patient would be surprised to learn about how they are accessing or disclosing their personal information, doctors should ask for explicit consent unless it is not practicable to do so.

We also say (paragraph 28) that if doctors rely on implied consent to access or share relevant patient information, patients should be fully informed about how their personal information will be used and that they have the right to object. We say that this can be provided in leaflets and posters, on websites, and face to face. The information should also be tailored to patients' identified communication requirements as far as practicable.

We believe that it may be helpful to clarify part of the revised wording in the Caldicott principle. We understand that the closing reference to patients and service users 'opting out' means them objecting to their confidential information being shared or used. However, in the context of the paragraph, opting out could also be interpreted as patients and service users objecting to having a conversation with healthcare professionals about how their confidential information is used. It may therefore be helpful to clarify this further.

6 Do you agree that the revised Caldicott Principles are a useful tool to help ensure that confidential information about patients and service users is used appropriately?

Agree

If you think it would be useful for us to know why please use the free text box to tell us.:

Comments regarding revised Principle 6:

We believe that it may be helpful to clarify the scope of the revised wording in the second sentence. For instance, does the wording suggest that individuals are responsible for ensuring that their own use of and access to confidential information complies with legal requirements, as set out in statute and under the common

law? Alternatively, could the sentence be understood as suggesting that individuals are responsible for ensuring that the use of and access to confidential information by others in their organisation complies with legal requirements?

Comments regarding revised principle 7:

We broadly support principle 7 but would like to make some observations about the revised wording. At the same time, we appreciate that the Caldicott principles will be subject to a degree of interpretation.

As we say in our guidance on this subject, confidentiality is an important legal and ethical duty, but it is not absolute. We recognise that appropriate information sharing is an essential part of the provision of safe and effective care.

We note that the revised wording refers specifically to 'information for direct care' rather than just 'information'. As mentioned, we agree that it is important that doctors share information for direct care. However, in focusing the revised principle on direct care specifically it may raise questions in doctor's minds about the importance of disclosures for other purposes, relative to the duty to protect patient confidentiality.

For instance, our guidance recognises that the purpose of some disclosures is indirectly related to patient care in that they enable health services to function efficiently and safely, such as medical research, service planning and financial audit (see paragraphs 77-8). We are also clear that there can be a public interest in disclosing information to protect individuals or society from risks of serious harm, such as from serious communicable diseases or serious crime (see paragraph 63).

The revised wording from 'can be' to 'is' also shifts the emphasis of principle 7. This could be interpreted as making the principle more absolute and suggesting that sharing information for direct care is always as important as protecting patient confidentiality.

While we agree that information sharing is an essential part of safe and effective care, we recognise that doctors sharing information with those who provide or support direct care will not always be appropriate. For example, at paragraph 10 we say patients must understand that they have the right to object to their personal information being shared for the purpose of their own care and that doctors must be satisfied their patients have not objected.

We say doctors 'should' as opposed to that they 'must' share information for direct care purposes. We use the term 'should' in our guidance where the duty or principle will not apply in all situations or circumstances, or where there are factors outside the doctor's control that affect whether or how they can follow the guidance.

Emphasising that sharing information for direct care is as important as protecting patient confidentiality may undermine the fact that, sometimes, sharing information for direct care may not be as important because the patient may exercise their right to object.

We explore this situation at paragraphs 30 and 31 in our guidance. In summary, we say that doctors should explain to the patient the potential consequences of not allowing personal information to be shared with others who are providing their care. If, after discussion, a patient who has capacity to make the decision still objects to the disclosure, doctors should explain that they cannot refer them or arrange their treatment without also disclosing that information.

Upholding the Caldicott Principles: the role of the Caldicott Guardian and NDG statutory power to issue guidance

7 Do you agree with the NDG's proposal to issue guidance that all public bodies within the health and adult social care sector in England, and all organisations which contract with such public bodies to deliver health or adult social care services, should have a Caldicott Guardian?

Strongly agree

8 What issues should NDG guidance about Caldicott Guardians cover? Please select all that apply.

Role and responsibilities, Competencies and knowledge required, Training and continuous professional development, Relationships to other key roles eg Data Protection Officer, Accountability, The types of organisations that should be appointing dedicated Caldicott Guardians, How small organisations could arrange a Caldicott function where it's not proportionate to have their own Caldicott Guardian

Other:

9 What additional support would be necessary to help implementation of the guidance?

Training for Caldicott Guardians, Information/training for senior staff/boards on the role of Caldicott Guardians, Peer-to-peer support for Caldicott Guardians

Other:

10 Is there anything else you want to tell us about the proposals in this consultation?

Comments:

In general, we would encourage the National Data Guardian to work with employers so that they're able to support doctors and other healthcare professionals in understanding and implementing the new and existing Caldicott Principles. We will continue to promote the Caldicott Principles and the supportive role of Caldicott Guardians in our work.

To assist doctors and other healthcare professionals in implementing the 8th Caldicott principle ('no surprises'), it's particularly important that employers provide appropriate support. For instance, this may include ensuring that doctors have ready access to leaflets, posters or digital information, which informs patients

about how their information is used.

11 We will treat all responses in the strictest confidence.

If you are happy for us to contact you to clarify your comments, please tick here and provide your email address below.:

Yes

Please tick this box if you would like to be alerted when the results of this consultation are published and provide your email address below.:

Yes

Email:

reactiveteam@gmc-uk.org