NDG Caldicott Principles

"Caldicott Principles: a consultation about revising, expanding and upholding the principles"

Response due by 3 September 2020

Response from use MY data

Introductory Note

This response has been coordinated by the Secretariat of **use MY data**, on behalf of members.

As with all the responses we collate on behalf of **use MY data**, these may contain contrasting views from members. It is inevitable that we receive a range of views from members, and all of these views are included in our response. We believe that there is strength in presenting a complete range of views.

Contact details and follow-up

Our members are happy for use MY data's response to be used or shared without restriction.

If you would like to follow-up with **use MY data**, or ask any questions about our response, please contact Chris Carrigan – chris@usemydata.org.uk

Our comments are shown below in red, and include points of feedback specific to the online questionnaire.

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

[✓ **Strongly agree**]

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Don't know

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.

“Good news and I think this fits well”

We note that Principle 7 has introduced the words ‘for direct care’. We think there will be concerns with this apparent moving back from a more positive encouragement of releasing data for legitimate research.

“This [change to Principle 7] has the potential to be a retrograde step and may make local Caldicott Guardians even more conservative in their advice on use of data for valid research.”

“Could Principle 7 give encouragement to Caldicott Guardians to support research where justified?”

“As a patient I am very pleased to see the clarification in Principle 7. However as a patient I am also worried by the absence of a similar principle about the duty for sharing data for ethically approved medical research. I would hope to see something like:

The duty to share information for legitimate (?ethically-approved) research to benefit patients in general is as important as the duty to protect individual patient confidentiality. “

It was suggested that this would probably need an explanation or caveat later on, perhaps something like:

“This needs to be done in the context of relevant regulation but nevertheless the emphasis should be on the need to use patient data to benefit patients. “

“….for me there clearly needs to be a separate and explicit principle about sharing data for research, and it is deeply disappointing that the NDG continues to omit providing such guidance, as the outcomes are that research is being delayed, made significantly more expensive, and even prevented entirely.”

"By limiting Principle 7 to 'direct care' only, these negative outcomes will become even more likely and research that will benefit patients and the NHS will become even harder to undertake. That is not what patients want and I am sure cannot be the NDG's intention."

Specifically on the new Principle 8, we would clearly support much better information for patents about how their data is used. We would support the principle of choice, alongside much more efforts to increase knowledge of the benefits of data usage that have been seen, and which could be accrued in future.

Our own guiding principles for Transparency are:

- Accessible - easy access to information
- Understandable - the right language for the audience
- Relevant - addresses audience concerns
- Useable - in a form that meets the audience needs
- Assessable - is checkable/provides sufficient detail
- Being as pro-active with 'bad news' as with 'good news'
- Being timely with communication

Question 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?

Strongly agree

[✓ Agree]

Neither agree nor disagree

Disagree

Strongly disagree

Don't know

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

"As a patient I am very pleased to see the clarification in Principle 7. However as a patient I am also worried by the absence of a similar principle about the duty for sharing data for ethically approved medical research."

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

Agree

Neither agree nor disagree

Disagree

Strongly disagree

Don't know

Though we would restate that guardianship should be seen alongside data-usage. Both are needed.

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 (please use text box below to tell us)

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 (please use text box below to tell us)

Greater use of patient groups to engage different communities an audiences.

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

Response submission reference: ANON-JE4C-RY2G-A

About use MY data

use MY data is a movement of patients, carers and relatives

use MY data supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

What we do

- We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.

- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.

- We provide learning resources for patient advocates on patient data issues, including:
  - hosting workshops for patients and the public, focussing on topics related to patient data
  - a library of resources of data security, consent
  - narratives from individuals about how collecting, storing and using data can help patients.

- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

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