



Confidentiality and Information Sharing for Direct Care

Explanatory notes and request for feedback

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Contents

Why are we publishing this guidance?.....	5
Annex 1 Questions.....	9

Why are we publishing this guidance?

Background

1. Nowadays many people find that the care they receive is given by many different people and many different organisations. We hear from people that, all too often, they find that they are faced with someone they have not met before and who has no information about them or their needs. We want to stop this from happening by helping frontline staff to make better sharing decisions every day.
2. Decisions about data sharing can be complex and it is important that staff are aware of the circumstances when they might need help in making sharing decisions. But most sharing decisions are straightforward and staff should be encouraged to share where there are no complicating circumstances and to seek advice when the decisions are more complicated.

Our aim

3. We want staff to feel that they know when they can share information, when they should ask for advice and how to get the advice they need.
4. In “Integrated Care and Support: Our Shared Commitment” published in May 2013¹ , we said:

In order to deliver person-centred coordinated care, data relating to individual's risk factors, identified needs, care plans and status should be shared at the following levels within appropriate time frames:

- *between patients, people who use services and care providers such as clinicians, to enable self-management and build independence; and*
 - *between front line workers, to enable coordination and continuity of care at transitions between services throughout the care pathway*
5. We expect localities to adhere to the principles of the Caldicott Information Governance Review Report (see below) and the NHS Constitution² on data sharing, in their efforts to integrate care and support for the benefit of patients and people who use services.

Evidence for the problem - from the Information Governance Review report 2013³

6. The report from the Information Governance Review (IGR) panel that was chaired by Dame Fiona Caldicott said:

¹

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198748/DEFINITIVE_FINAL_VERSION_Integrated_Care_and_Support_-_Our_Shared_Commitment_2013-05-13.pdf

² <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>

³

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_a_ccv2.pdf

When it comes to sharing information, a culture of anxiety permeates the health and social care sector. Managers, who are fearful that their organisations may be fined for breaching data protection laws, are inclined to set unduly restrictive rules for information governance. Front-line professionals, who are fearful of breaking those rules, do not co-operate with each other as much as they would like by sharing information in the interests of patients and service users. There is also a lack of trust between the NHS and local authorities and between public and private providers due to perceived and actual differences in information governance practice.

7. The panel found a strong consensus of support among professionals and the public that safe and appropriate sharing in the interests of the individual's direct care should be the rule, and not the exception and concluded that providers in the health and social care system may benefit from reviewing and improving their policies for sharing to ensure they are focused on the patient or service user's best interest, taking account of the safety of people providing care.
8. The panel also concluded that when a patient does NOT want to share some or all of their personal confidential data with a health and social care professional this should be noted in the person's direct care record. The risk of not sharing the information should be explained to them, but in general, their wishes should be respected.
9. The Review Panel concluded that a registered and regulated professional's primary concern must be for the health and wellbeing of the individual to whom they are providing direct care and the presumption should be in favour of sharing for an individual's direct care.
10. As part of this, professionals have a responsibility for accurately communicating information, ensuring that the recipient understands any particular issues or conditions that apply, such as safeguarding issues, or whether individuals have expressed particular wishes in relation to onward disclosure that should be respected.
11. The Review Panel concludes that for direct care, when a professional is satisfied the recipient has a legitimate relationship with the patient, and that the recipient understands any particular issues or conditions that apply, the information can be shared with the individual's implied consent. The recipient then becomes responsible and accountable for that information in a professional capacity.

What is available already

12. There is already in existence a lot of detailed guidance and advice including
 - HSCIC Guide to confidentiality
 - DH Code of Practice on Confidentiality
 - Professional regulators guidance
 - Data Protection guidance from the Information Commissioner's Office
 - And many publications covering specific areas in detail

There is a list on the IG Alliance website⁴

⁴ www.hscic.gov.uk/iga

How does this new guidance help

13. This new guidance is designed to tackle the particular problem identified by Fiona Caldicott and her panel – that frontline staff do not co-operate with each other as much as they would like by sharing information in the interests of patients and service users because they are fearful of breaking the rules.
14. This guidance lays out the rules of information sharing as they are applicable to frontline staff. The top message is that where the person has full capacity to decide and has no concerns about the relevant medical information being shared with those giving them care, the decision to share should usually be straightforward and made with the knowledge of the individual.

What are we seeking feedback on

15. We want to know if this document does help frontline staff at the point where they are making better data sharing decisions along the pathway of care. We want to know whether we should change the document to make it more useful and what else is preventing frontline staff from making decisions in favour of data sharing along the pathway of care. A list of questions to prompt discussion is at the end of this document.
16. We must ensure that we have due regard to the three aims of the Public Sector Equality Duty and the Secretary of State's for Health's duty to have regard to the need to reduce health inequalities⁵. We welcome feedback on these questions.

What is out of scope

17. The legal framework

This guidance does not set out the complex legal framework in which these decisions are made because frontline staff are not expected to understand the legal framework in detail and it is not appropriate for them to refer to complex guidance as they are making day-to-day decisions. There is already guidance on the legal framework on the IGA website.

18. Information for IG leads, Caldicott Guardians and others who provide advice to frontline workers

IG Leads and Caldicott Guardians should be familiar with the guidance that is appropriate for their organisations. A full list is in the IG Toolkit⁶. The IGR report looked at training and education needs of these experts and made separate recommendations in this area. The Department of Health is considering further action on training and education.

19. Technical issues with sharing of electronic records

A number of projects are working on the sharing of electronic records including the Integrated Digital Care Technology Fund⁷.

⁵ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/276682/2014_services.pdf

⁶ <https://www.igt.hscic.gov.uk/resources.aspx?tk=419443803590880&cb=2a5237c2-44d2-4003-82c8-05594f5ff71c&lnv=8&cnav=YES>

⁷ <http://www.england.nhs.uk/ourwork/tsd/sst/tech-fund/>

20. Organisations' policies and procedures

Managers, who are fearful that their organisations may be fined for breaching data protection laws, are inclined to set unduly restrictive rules for information governance. This guidance is not intended to address this although it may help to set the expectation that these unduly restrictive rules should be changed. We encourage IG leads, Caldicott Guardian and senior managers to examine and challenge organisational policies where they are unduly restrictive or not aligned with the revised Caldicott principles⁸

21. Perceived lack of trust between organisations

The guidance will not address the perceived lack of trust between the NHS and local authorities and between public and private providers due to perceived and actual differences in information governance practice.

How to provide feedback

22. We are running a small number of workshops but you can also run your own workshop using the material on the website. If your workshop needs the material in a different format, please let us know. You can complete the form on the website with your comments and email your responses to iga@nhs.net
23. Please respond by Friday 31 January 2015.
24. Depending on what we hear, a final version of this document will be published in 2015.

⁸ See IGR report (*ibid*) page 118

Annex 1 Questions

Question 1: Think about how you make decisions to share information about individual patients or service users with others who are giving care to that person.

Do you understand this document?

- Yes
- No – please explain what is unclear

Question 2: This document is designed to be used when frontline staff are making decisions about whether to share information about a person with someone else who is giving care to that person.

It reminds staff that they should take into account the person's preferences, the need to share and the obligation of confidentiality in making decisions about what, if anything, to share.

What problems do you have when trying to make decisions about this sort of information sharing?

- I don't make these sort of decisions
- I don't have any problems making these decisions
- I do have problems making these decisions (specify)

Question 3: Thinking about this document, please answer the following questions with 1 being "not at all" and 4 being "completely"

	1	2	3	4
Does this document provide clear and accessible guidance on information sharing?				
Does this document explain how to make decisions about sharing information?				
Does this document give you help or support to make these decisions?				
Does this document make it easier to make these sharing decisions?				

Question 4: How could the document be improved to make it more helpful?

Question 5: What suggestions do you have for getting this document used widely?

Question 6: Do you know of any examples where data sharing is happening successfully?

Question 7: We think that the advice in this leaflet has no impact on work on equality issues or on work to reduce health inequalities. Do you have any comments on this?

Question 8: Do you have any other comments?

Question 9: Do you make decisions about sharing information?

- I am a patient or a user of care and support services
- I make decisions about whether to share people's personal information as part of my work
- I give advice to those making such decisions
- I am responsible for policies and processes relating to information sharing in my organisation
- None of the above (please specify)

Question 10: Where do you work?

- I am answering this questionnaire as a member of the public
- Specify organisation
- I prefer not to say

Please respond to iga@nhs.net by 31 January 2015