



Information – to share or not to share?... What Patients want!

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IG Review: Information: To share or not to share?

- Introductions
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- Summary, Conclusions, Next steps
- Questions, Comments

IG Review: Information: To share or not to share?

Aim

To make recommendations to the Secretary of State for Health on:

how to achieve a better balance between protecting and sharing confidential personal information.
For Health & Social Care

Approach

- Independent expert panel chaired by Dame Fiona Caldicott
- Evidence being collected around key themes

www.Caldicott2.dh.gov.uk



Findings

Nine sessions captured the views of patients, service users and carers re key issues & suggested best practice/solutions ...

1. Current experiences & expectations around information sharing and privacy;
2. Future wants & expectations around access to & control of information for purposes of direct care;
3. Future wants & expectations around information usage for purposes other than direct care.

Current experiences & expectations around information sharing and privacy ...

- 1. **No harm from professional judgements re sharing vs harm & distress from not sharing** – perceived consequences varying from delays to fatalities;
- 2. **No surprises principle** - multiple clinicians do not share as expected so history needs to be repeated;
- 3. **Health and Social Care Departments don't share as expected** with negative consequences re benefits payment, military records not transferred etc.

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No harm from sharing vs harm from not sharing

Future wants & expectations around access to & control of information for direct care ...

1. Access to their records & copies of correspondence in a **format they choose**, for purposes such as checking for accuracy & sharing with support groups;
2. Expect their information to be shared with ***regulated and registered*** professionals providing their direct care;
3. Vulnerable adults (with capacity) want to be **consulted first** on sharing decisions. Carers should be involved in decisions where [a] the patient (with capacity) has consented, and [b] the carer has consented - **double consent**.

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If you care, share

Future wants & expectations around information usage for non - direct care ...

1. Information sharing for **research was well received**, particularly for public good purposes - the deadlier the disease and more direct the benefit, the greater support;
2. **Commercial use of data was not as well received** – use of data for commercial profit was largely unsupported;
3. Patients should be **asked for consent first** to use their data for commissioning, service planning, audit etc. Use of patient identifiable data for these purposes was not supported/understood. How anonymous is anonymous?...

[graphic removed]

IF you need identifiable data, ASK... we're more inclined to share if we can see the benefit to direct care

IG Review: Information: To share or not to share?

Caldicott Review vs IG Toolkit Review

1. Independent and unrelated, although fully aware of each other;
2. **Caldicott led by Secretary of State**, whereas IGT led by DH/NHS;
3. Both take note of healthcare professionals' views;
4. Caldicott much more interested in views of patients and carers, whereas IGT concerned about proper IG management;
5. Caldicott feels more strategic, whereas IGT review is about practical implementation issues;
6. IGT is reviewed regularly, whereas Caldicott is a one-off (or two-off!)

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A future IG Toolkit Review might well implement some of the Caldicott Review recommendations

Summary, Conclusions, Next Steps...

1. IG is a big issue for patients - they want more sharing for direct care, and to be asked about sharing for non-direct care. Equal starting point (and repercussions...) required for professional decisions re:
 - Sharing across Social Care **and** Health
 - Sharing **and** Confidentiality
2. Report & recommendations being drafted for Secretary of State - Publication Spring 2013
3. Intention to contribute to the consultation on the NHS Constitution

Website: www.Caldicott2.dh.gov.uk

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...Questions...