

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

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# **Ted Woodhouse**

with the support and agreement of Christina Munns (DH Information Governance Review)

- Introductions
- Aims & Approach
- Findings
- Summary, Conclusions, Next steps
- Questions, Comments

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

#### Aim

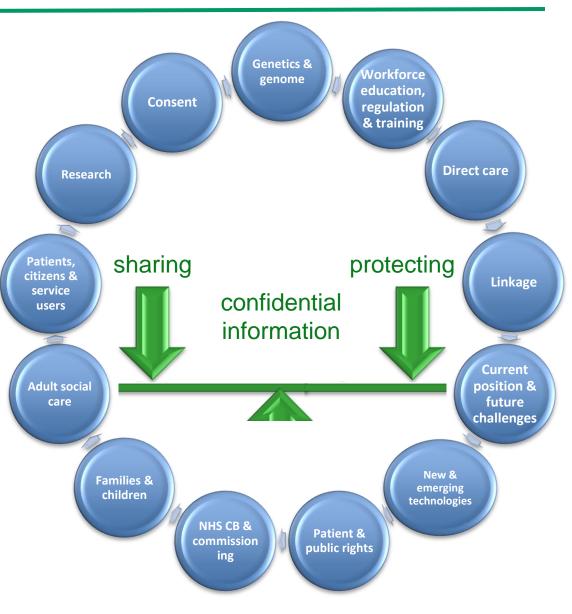
# To make recommendations to the Secretary of State for Health on:

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





# **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 ...

- 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.

#### 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**.

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?...

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

### **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;
- 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!)

#### 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: <u>www.Caldicott2.dh.gov.uk</u>

Join in the discussion on twitter: #caldicott2 @caldicott2

## ...Questions...