



HSCIC Stakeholder Meeting : Driving Positive Change

21 July 2014, King's Fund, London

Summary discussion notes

Governance

Overarching Message: Clarity around deletion, inter government sharing, commercial/intermediary use, Audit criteria, IG controls.

- Clarity on CAG role
- Clarity on DAAG role
- Pathways; could we have a pathway for data requests
- Data quality standards for intermediaries and end users
- Documented process/proof of consent and legal basis for release approval – include non-approvals
- Clarity around the audit process and what it means
- Provide assurance that the Tracing/NBO/UK Border Agency issues would be looked at again
- End the use of commercial reuse licences and communicate that this has been done.
- Explore gold standard type accreditation process

Sanctions and Penalties

Overarching message: Clarity on the levels of sanctions and penalties and how these apply at an organisation, department and individual level.

- Seriousness of breach
- Financial sanctions and fairness
- What if Government bodies make the mistake

Consent

Overarching Message: Implications for blanket opt out. Global opt out could override individual study consent. Make clear risks versus benefits. Make clear options.

- Multi layered opt in/opt out : ideal model and ethical consent challenge?
- What is the action on opt-out? Put power into hands of the patient
- Opt-out vs deletion of data
- Deliberative workshops to look at different options for sharing

Communications

Overarching Message: Need to improve our communications with customers, stakeholders, partners and the public.

- Provide more frequent progress reports including updates on pipeline backlog activity, new processes and when will they come into effect
- Specialist forums/meetings
- Provide guidance/tools on the different data types, pseudo, aggregate, identifiable
- Transparency around who is using data and why including commercial use
- Transparency of data release process and customer progress through each stage
- Fair processing type portal (public, others)

Public Engagement

Overarching Message: Need to improve patient/public awareness, involvement and understanding. Build trust through joint working approach with a range of bodies and advocates/champions

- Choice and consent – provide clarity on what public can and cannot object to
- Clarity on the protective mechanisms in place for the public
- Build trust by working in partnership with respected third sector, professional bodies and partner organisations who can champion/advocate
- Clarity around data use by stating what it is used for and what is it not used for
- Tell the public the benefits of sharing data, use case studies to describe positive ways the data is used
- Dialogue on Data : ONS research paper
- Foster trust worthiness (transparency of governance; opt-out, redress for when things go wrong)
- Transparency around the criteria for appointing public representatives on groups /board
- Set national standards for patient representatives (example : in some cases deputies not allowed)
- Allow patient reps to be shadowed at meetings as part of learning (wider pool of public reps)

Data Laboratories

Overarching message: Provide clarity on scope, capacity, capability, governance, accreditation and process for user fast track. Ensure approach flexible not one size fits all.

- Provide clarity on the differences between secure data labs and accredited safe havens and how they will work together
- How do you take tools and data etc to labs?
- Clarify consultation process including how we get involved

- Will customers have to go a data lab in person?
- People want data in-house at times – provide accreditation for this?
- The term ‘data lab’ sounds secure to patients – this is a positive message
- Could another org push data into the data lab
- What type of data will be available in data labs?
- May inhibit the sharing of data across different organisations and multiple sources
- Technical challenges, could stifle innovation and become bottleneck
- Connect with the Administrative Data Research Network as they are dealing with many similar issues
- Look to Farr Institute and DataShield