Feedback from Information Governance Working Group

November 2015
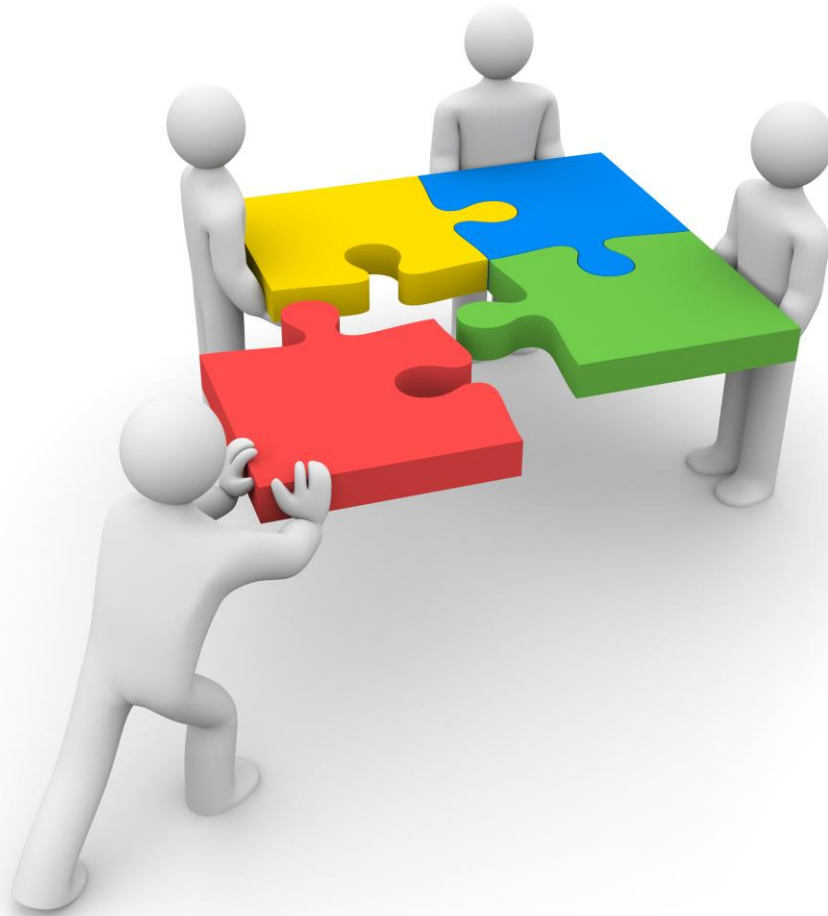
Malcolm Teague, Jisc, WG Facilitator
On behalf of Bridget Kenyon, Head of Information Security, UCL

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ABOUT THE GROUP

Purpose

- Liaise with Health and Social Care Information Centre (HSCIC)

- Represent the views of higher educational institutions affected by the IG Toolkit

- Suggest alterations and additions to the Toolkit

- Provide advice and support to HEI specialists working towards Toolkit adoption

Membership

Currently, 73 members representing:

- 25 HEI institutions (was 21)
- 3 Research organisations (unchanged)
- 1 NHS trust
- 1 commercial body
- 1 independent (unchanged)
- HSCIC
- HRA, PHE
- Jisc

All started from a workshop in March 2013

RECENT ACTIVITIES

IG Working Group meetings and events

- 8th January: meeting
- 3rd February: workshop and training day
- 17th March: meeting re HSCIC Framework Agreement (FA)
- 31st March: conference call re FA
- 15th May: meeting and IGAF2 workshop
- 15th October: meeting, 23 attendees

IG Toolkit developments

- Version (13) published in June
- New assurance framework (IGAF2) version released as a trial in Sept. 2015:
  - Specifically designed for independent contractors (general practice, dentistry & ophthalmic) and care homes
  - Aim to balance the language of the IGTK for health and social care
  - Following a Working Group workshop with HSCIC in May, decided that research IGT views should not be included.
- Proposed amendments for v14 needed in Jan 16

HSCIC Data Sharing Framework Agreement

- Contract created to address the concerns in the Partridge report

- Governs sharing of HSCIC-controlled medical data (ONS, HES etc)

- Intended to create a single "gateway" for requests for personal data by organisations

- Intended to achieve a consistent approach

- Requires IGTK, ISO/IEC 27001 or "other" certification

Framework Agreement issues

- Contract terms:
  - Scope of applicability (organisation-wide)
  - Assumption of strongly centrally controlled organisation
  - No provision for charitable institutions
- Signing:
  - Some institutions have signed, and some have not
  - Serious problems in getting data (in some cases)
- Engagement:
  - Introduced rather suddenly
  - Original strongly stated HSCIC aim to work with institutions to devise a common document
  - Subsequent revision of position to "no change to the documents in use, and retention of multiple versions"

Framework Agreement Update

- Issues were being dealt with at a higher level
- WG had liaison with:
  - UKCRC Regulatory and Governance Forum
  - Health Statistics User Group (HSUG)
- David Evans of HSCIC attended last WG meeting – announced review of Data Sharing Framework Contract and Data Sharing Agreement (by 30/11)
- We responded to the review with the previously agreed position, WG members responded individually if they wished as well. Waiting to see the outcome.
- David Evans now leading the audits, able to discuss experiences e.g. with Leeds who had recently been audited.

Other developments

- Attendance from the Strategic Account Manager, Research and Life Sciences from the Data Dissemination Group at HSCIC, they run the Data Access Request Service (DARS) – being reviewed
- Regularly attending SIGN meetings
- HRA – positive workshops on IG approval, questions been revised – draft MoU with Wales on IGT equivalence
- Update on local developments from members
- Creation of CareCERT, Caldicott review of data security – Jan 16.

PLANS

Next steps

- Escalate Meeting Dec 15 to agree IGTK v14 proposals and prepare for:

- IGT Workshop Training Day in late Jan/early Feb 2016

Conclusion

- Successful collaboration with HSCIC on the Toolkit

- Improving collaboration with HSCIC on Framework Agreement and DARS

- Working Group would propose to continue in operation

- Contact Malcolm Teague to get involved:

  - malcolm.teague@jisc.ac.uk