

NHS HE Information Governance Working Group

Notes of Meeting on 21st March 2016

Present:

Nigel Bailey (NBa)	KCL
Richard Bartlett (RB)	University of Cambridge
Norman Bridges (NBr)	University of Keele
Andrew Burnham (AB)	University of Leicester
Tom Chan (ToC)	University of Surrey
Tim Chater (TiC)	University of Sheffield
Wendy Craig (WeC)	University of Newcastle, by teleconference
Will Crocombe (WiC)	University of Leeds
David Evans (DE)	HSCIC
Gearoid Garvey (GG)	UCL
Susan Graham (SG)	University of Edinburgh, by teleconference
Huw Gulliver (HG)	Cardiff University
John Hodson (JH)	HSCIC
Bridget Kenyon (BK, Chair)	UCL
Trevor Peacock (TP)	UCL
Jethro Perkins (JP)	LSE
Lindsay Shure	UCL
Malcolm Teague (MT)	Jisc
Haiyan Wu	QMUL
Tee Wu	QMUL
Apologies:	
All other group members	

Minutes of the meeting of 15th October 2015

- 1 These were agreed.

Update on Actions from previous meetings

- 2 For previous actions still open then please see the open actions summary list at the end. The actions that were closed were:

Ref.	Action	Who	Update
3.1	Letter to be drafted from the Working Group that can be forwarded to appropriate groups registering for the IGT.	BK	MT to amend letter and reissue to VK. Update 15/05/15: Letter has been redrafted. Comments received from VK and BL for incorporation. Update 15/10/15: Updated near final draft agreed with BK and JH, final touches and then implement. Update 21/03/16: JH reported that he was now sending a letter out to new IGT applicants informing them of the Working Group. Closed

11.1	More detailed discussion on the way forward for potential hosting and updating of NIHRCC training package to be on the agenda for the next meeting.	MT	On the agenda. Closed.
11.2	To recirculate the proposed changes to the framework agreement previously agreed, and to incorporate them in to the draft response from the group to the public review of the Framework Agreement.	MT	Complete. This was used as the Working Group's response to the consultation.
11.4	To circulate a list of those representing research and education on the DARS subgroups.	ES	Complete

Update from David Evans, HSCIC

- 3 DE, although he has now moved to auditing the framework contracts, reported that there had been a lot of work on Type 2 patient objections to their data being used for secondary purposes. The Secretary of State has said that these will be honoured.
- 4 DE thanked everyone for the responses to the consultation on the frameworks contracts and data sharing agreements. There had been feedback from 51 organisations or individuals. 80% were positive with 20% asking for improvement. 577 comments overall.
- 5 One issue that had come up was sub-licencing and this will require input from the lawyers. A lot of preparation work has been done.
- 6 DE said for those people where the contract is coming up to the end, they will get a year extension.
- 7 There was some discussion on various aspects e.g. difficulty with federation, detail asked at the contract rather than data sharing agreement level.
- 8 DE also reported on the audits. The plan was that there would be 25-30 each year, about a tenth of the customer base. Who would be audited would be decided on a risk-based approach, but they will sample low risk projects as well. Some audits so far have found a few scary things.
- 9 The Auditor reports will be published and DE agreed to circulate the url for that. {post meeting note – these are at <http://content.digital.nhs.uk/dsa>
- 10 BK said it would be incredibly helpful to have a summary of the main finding in a standard format for loading in to other tools e.g. csv format. AB said Leicester had been audited recently and he had put the findings on a spreadsheet.

- 11 NB said KCL had an audit last year and got through it OK, but then had lots of questions asked afterwards, many of which were covered by the audit.
- 12 DE mentioned that there has been progress with the new European Data Protection Legislation. A new code expected from the ICO. Bit by bit then likely to influence the release of data and will bring about changes. The part that covers medical research still missing. SG said she thought that medical research elements had been devolved to member states, and in the UK with the Department of Culture, Media and Sport.

HSCIC IGT Update

- 13 JH that the deadline for NHS organisations to complete IGT version 13 was 31st March 2016. About 75% of organisations that are expected to publish with version 13 have already done so, but typically have 6,000 IGTs trying to be published on 30th and 31st March. So a very busy time.
- 14 IGT v13 ceases to be current on 1st April 2016 and then v14 will be launched. IGT v14 is ready but is waiting on the Dame Fiona Caldicott report on her security review in health and social care in case there are any proposals that could be included. However the report was supposed to be provided by January but it is not yet available and EU referendum purdah will hit soon. So v14 may not be that much different to v13.
- 15 JH said with it being such a busy time with the NHS IGT assessments, to let him know if there is a problem with DARS or CAG requests, 16 in the queue at the moment.
- 16 The DARS event on 14th March 2016 was mentioned, at UCL. JH had attended and then also met with the DARS panel for an IGT training day. He noted that all the details will have to be supplied in future for “satisfactory with improvement plan” (previously just took the “satisfactory”). The improvement plans will need to be in the toolkit rather than on a separate spreadsheet. DARS could choose not to give out data on the basis of the improvement plan not being sufficient reassurance.
- 17 There was no news on the outcome of the “accredited safe haven” consultation

SIGN Meetings

- 18 Not one recently, next due on 14th April.

Updates from Members

- 19 The following updates were given:
- UCL – TP said no audit yet, signed off contract, agreed the contract that had previously signed while waiting for the new one to come through. Had missed the DARS event but had heard it had been quite successful.
 - LSE – JP said that LSE are going for ISO 27001 rather than IGT. Creating an environment for other sensitive data as well and doesn't preclude IGT. Very limited scope. 4 DSAs under framework contract.
 - Leeds – WiC said no further audits since last time. Serial number issue had been resolved. Raised issue of “old consent”. Is meeting with someone from NIHR Clinical Research Networks Coordinating Centre. It would be good to rebuild that relationship after Kirsty Benn-Harris moved to Monitor (now NHS Improvement).

- Sheffield – TC said they had an audit in October. Some minor non-conformities and now working through the plan. Working on revised IGT submission. Issues on framework agreement. More concerned about the stringent requirements in the framework – feels the framework should be about principles.
- KCL – 6 or 7 DSAs, all based on the “other” option. Had to work at making sure the audits happened. There are some groups that have done IGT in the past. Had been one audit, 2 points and 8 observations. Had made KCL do things they didn’t want to do for a small project but had also been a “good nudge” to do some things. NBa said he wanted to find all those little places and if they have an IGT then what are they doing? Don’t want cheating to be taking place. JH said he had a list of KCL IGTs and would send to NBa.
- Newcastle – WeC has become the IG Lead for Newcastle, tweaking the UCL approach to fit the University. Running a similar event to that held at UCL on DARS on 16th May, open invitation to the working group. Hoping that by 31st March will have the first IGT at Newcastle. Probably going to concentrate on projects rather than aim for institutional. An issue is partner Universities in London, Malaysia and a few other places.
- Leicester – AB said Leicester have a renewable framework contract. Audited against one of the DSAs a couple of weeks ago. Interesting time. Bit confused about who we were. Thought it was a hospital but University department in the hospital site. The audit was difficult in terms of whom should take control and who should be involved. Few non-conformities. Researcher did look quite worried for some time. It was good that auditors don’t mind sharing experience.
- Keele – NBr said have framework agreement until July. 2 DSA, all OK at the moment
- Surrey – ToC said no HSCIC audit yet but doing an informal one with the local CCG.
- QMUL – TW is at the Wolfson Institute of Preventative Medicine. They have a separate network from the University since early 2000s. Have done internal audits and another for remote access. In last two years have been inviting University security manager to review IGT. Done twice now. For University level, 2 audits & MRHA inspection. Also a security company to check the 3 IGTs. Central IT is going to do a gap analysis against IGT.
- Cambridge – RB said they had received the same DSA questions back on IGT renewal. They had an internal ISO27001 audit, aiming for reduced scope in June but want to extend to outside the direct scope in future.
- Cardiff – similar to others

20 In the updates, one of the issues mentioned was the difficulty with making deletions where that is asked for, or the mechanism asked for. WeC said they had a rolling 6 month back-up so takes time to work through and no way at the moment to do it earlier. **Action 12.1:** DE to check on timescales for deletion and to put the answer in writing if possible. TP said that he had discussions with Mike Gallagher on data deletion and agreed some text, can circulate if of interest.

21 Another issue raised by WiC at Leeds was that of using data that had consent, but this had been given a long time ago. Either consent or s251 has to be in place as a legal basis to flow (letter from Terry Hill). Putting up information on a website to explain what was happening had been advised. In WiC’s experience there was more interest in what had been the outcome of the research rather than the consent. It was thought that showing that the consent issue has been considered and efforts made to keep patients informed. DE said that in the example of consented data being used for the original aim but now something further is proposed, then need to go back to CAG for that.

Future Activities/Date of next meeting

- 22 BK suggested that it would be good to have a more informal get together with HSCIC representatives, to get to know them better. BK suggested a “coffee morning” type of event in Leeds for a face to face as human beings! This was agreed as a good idea, will aim for this to be in June. It was suggested Caldicott Guardian and SIRO involvement would be good.
- 23 Still planned to have a Training Day/Workshop at the end of the year or early 2017. Topics suggested included Caldicott Report outcomes, new Data Protection requirements and audit team experiences.

Summary of Open and New Actions:

Open actions:

Ref.	Action	Who	Update
3.2	Provide IGT to ISO 27001 and 27002 mapping for Secondary Use view.	BK	BK reported that an initial analysis had revealed 200 pages of difference so this will take a while. Update 15/10/15: JH said that Darren Mort at HSCIC has this as ongoing project. Will wait for the outcome of that work. Update 21/03/16: Carried forward.
6.2	Contact Natasha Dunkley to chase up the proposed introductory letter about the Working Group to s251 applicants	BK	Update 15/05/15: Carried forward as for Action 3.1. Once Action 3.1 is done then VK will forward a copy to Natasha. Update 15/10/15: MT to forward new letter to ND as soon as it is agreed. Update 21/03/16: This can now be done as action 3.1 is complete.
7.1	Comparison of ECRINS with the IGT.	LS	Update 15/10/15: Carried forward in LSs absence. Update 21/03/16: carried forward.
7.2	Provide a one page summary on ECRINS to VK so she can explore it further from the HSCIC perspective. (would now be to JH)	WC	Update 15/05/15: WC will take on this action from KH. Update 15/10/15: WC reported that the ECRINS standard is being updated. Waiting for that to be finished to complete this task. Update 21/03/16: WC reported that no-one has yet signed up to this in the UK although it is thought to be the direction of travel. CTUs can see a reasonable amount of potential value.
7.15	Provide an example action Plan and MT to have a first go of doing this for the Working Group.	MT	VK has sent through the example. MT to change it to reflect the needs of the working group. Update 21/03/16: Carried forward.
8.8	Try again to create a list of IGT contacts at each	MT	Carried forward. Update 15/05/15: Suggested an extra column is shown that indicates whether

	institution		the organisation is trying a wider scale approach to IGT. AB is now doing this for Leicester. It would be good if the list can be on a website for reference. Update 15/10/15: MT has email group members to try to reinvigorate this. MR suggested that email addresses should not be included on the list if on the web. JH said it would be really useful for second line support. Update 21/3/16: MT had made a few more contacts but not much progress to report.
9.2	Ask at HSCIC about the output of the incident reporting and Accredited Safe Haven surveys.	JH	Carried forward. Update 15/10/15: JH said that he did not yet have outcomes from the surveys but that he could tell the group that there were no reported incidents from HE. Update 21/03/16: no further information on these.
10.1	Check funding and potential venue for proposed Training Day	MT	Expectation was that this is supported, more detail needed on potential date so that it could be created as an official request to Jisc. To be discussed on agenda. Update 21/03/16: Awaiting further discussion on plans, ongoing.
11.3	To check whether the facility will exist where the lead for an organisation will be able to see what has been applied for in their name and to give a coordinated view of all applications in DARS.	ES	No report in ES's absence.
11.5	Circulate the link for the IGA guidance on honorary contracts	JH	
11.6	Arrange Training Day in January or early February 2016	MT	As for 10.1

New Actions:

Ref.	Action	Who
12.1	Check on timescales for deletion and to put the answer in writing if possible.	DE