

NHS HE Information Governance Working Group

Notes of Meeting on 24th January 2014

Present:

Kirsty Benn-Harris (KBH)	NIHR CRN Coordinating Centre
Kyriakos Hatzaras (KH)	Kings College London
Vanessa Kaliapermall (VK)	HSCIC
Sarah Lawson (SL)	NPEU, University of Oxford
Janet Messer (JM)	Health Research Authority
Ravi Miranda (RM)	Institute of Education
Trevor Peacock (TP)	UCL
Malcolm Teague (MT)	Janet
Apologies:	
Athanasios Anastasiou (AA)	University of Swansea
Stuart Bloom (SBI)	Independent Consultant
Sally Bridges (SBr)	Health Education Kent Surrey Sussex
Andrew Burnham (AB)	University of Leicester
Tito Castillo (TC)	University of Cambridge
Will Crocombe (WC)	University of Leeds
Michael Hollis (MH)	Institute of Cancer Research
Bridget Kenyon (BK, Chair)	UCL
Lucy Lucas (LL)	HSCIC
Lee Moffatt (LM)	University of Manchester
Paul Newton (PN)	HSCIC
Debbie Ranger (DR)	University of Warwick
Marion Rosenberg (MR)	London School of Hygiene & Tropical Medicine
Julie Sherriff (JS)	University of Warwick
Christopher Walker (CW)	University of Leeds
Alyson Williams (AW)	University of Manchester
Hawys Williams (HW)	Arthritis UK

Introduction

- 1 In BK's absence SL agreed to Chair the meeting. SL welcomed everyone and in particular KH from KCL as it is his first meeting since joining the group.

Minutes of the Meeting & Workshop on 12th November 2013

- 2 These were agreed subject to some specific proposed amendments from VK for paras. 17, 20 and 22. **Action 4.1:** VK would provide some rewording to incorporate in the final minutes.

Matters arising not on the agenda

- 3 MT asked VK about any updates on the previous work reviewing the IGT application process. VK said that the suggestions were reviewed and she will be able to share a next draft version in due course.

4 VK gave a brief HSCIC update:

- The release date for IGT version 12 has been confirmed as June 2014
- So a lot of pressure to have all proposed changes in the system for the end of January. The main sources of proposals this year are:
 - i. LA view working group
 - ii. DH ISO standard updates
 - iii. This group
 - iv. General updates
- The project manager will be working through the editorial system in February and then there are a couple of review cycles, plus formal agreement through the Information Standards Board, before the release in June.
- HSCIC team currently more short-staffed than before with some leavers, but there are a couple of new starters so the position should improve once they are up and running.
- There is now a "[Change Request](#)" page and form on the IGT website. It includes a new change request button and process – a request can now be made at any time.

Update on Actions from previous meeting

5 These were as follows:

Ref.	Action	Who	Update
1.4	Review existing guidance around use of safe havens in relation to secure transfer of patient data between the NHS and research and education organisations.	MT	Carried forward except request to discuss under a proposed change to the IGT guidance.
1.6	The Working Group will include in its output guidance on local formal notifications to the DPO as at least a stop gap measure.	BK	The wider NHS-HE IG group could be emailed about this in the first instance, also a mention in the update at the next NHS-HE Forum. Carried forward.
2.2	Report the suggestion of a customer representative to the IGT Editorial Board.	VK	VK has raised this with Marie Greenfield and she took it as a suggestion to the IGT Editorial Board. The Terms of Reference for the IGT Editorial Board are still being determined. Awaiting feedback, not a "no".
2.5	Add an extra column to the list of contacts to indicate the approach the University is taking.	MT	Extra column added and request to complete has been sent to known contacts. Closed.
2.6	Ask permission of the contacts that the list of IGT	MT	This has now been done, awaiting feedback. Closed.

	contacts can be published on the website.		
3.1	Letter to be drafted from the Working Group that can be forwarded to appropriate groups registering for the IGT.	BK	A draft is with BK and VK. VK suggested the letter might be useful on the Confidentiality Advisory Group (CAG) web pages to pick up those investigating what they should do for the IGT. Action 4.2: VK to liaise with Natasha Dunkley at the HRA about this.
3.2	Provide IGT to ISO 27001 and 27002 mapping for Secondary Use view.	BK	Carried forward.
3.3	TC to share ISO 27001 to IGT mapping document with BK.	TC	Carried forward as far as is known in BK and TC's absence. TP offered to contact TC. TP also noted that UCL are looking to move to ISO 27001 accreditation for the wider group, and a project has been kicked off to do that.
3.4	Ask SBI if he might consider updating the mapping for the 2013 version of ISO 27002.	BK	Carried forward. VK said that there is a mapping between the 2005 and 2013 versions of ISO 27001 which is being used by the HSCIC. Action 4.3: VK to circulate the link to the mapping between ISO 27001 versions. VK noted that the other mappings that BK did were used as a basis for further work by HSCIC.
3.5	Circulate an update to the group of the work that is going on to update the map of the IGT with the PSN Code of Connection.	VK	This was done soon after the 12 th Nov meeting. Closed.
3.6	Provide a list of key documents expected to help with checking for gaps in the exemplar resources.	VK	VK reported that LL had a draft of this which was briefly discussed. VK will check position with LL and distribute to the working group asap.
3.7	MT to set up JISCMail list.	MT	Complete. Closed.
3.8	Add documents on to JISCMail list and ask for comments, possibly in a phased way.	SL	Process started with IG Policy documents. Closed.
3.9	Review the test CRN Training Package	VK	Complete (noting that this does not imply endorsement as the HSCIC does not do that)
3.10	Send through the proposed changes from the Workshop	MT	Complete. VK reported that she had heard back that it was an appropriate format and level of

	to VK as soon as possible, partly to check the process and level of information provided.		detail.
3.11	Raise wider use of IGT e.g. with Research Ethics Committees with the HRA	BK	Complete as JM from HRA in attendance. JM noted that the Research Ethics Committees are only constituted to deal with the ethics requirements and not with legal and security/confidentiality requirements. A few do stray in to the legal compliance area without this being their expertise. The HRA have a bid in to the Department of Health to bring alongside the legal compliance requirement with the ethics review. If the bid is successful then that will be a significant help. If it not successful then the HRA would be looking to get more input from the CAG team to support research ethics Committees a bit more than currently. TP said that in the IRAS system for the application to CAG you have to address each data protection principle and have a letter of support from the Caldicott Guardian. JM said that there are plans to replace IRAS and in the process have a big refresh of the information governance aspects.
3.12	Raise wider use of IGT, e.g. with Research Ethics Committees, with the ICO	VK	Complete

Any further and final suggestions on the IGT requirements

- 6 The day of the meeting was the final deadline for any further proposals for IGT requirement and guidance changes for consideration for version 12 to be released in June. MT had circulated the suggestions already made.
- 7 MT proposed adding to the guidance for requirement 11-223 (All transfers of personal and sensitive information are conducted in a secure and confidential manner) so that the listed “Appropriate Transfer Methods” include secure electronic transfer, as had been discussed by the group on 12th November. **Action 4.4:** MT to draft this proposed change and circulate to the group for comment immediately after the meeting.
- 8 There were no further suggestions from the group. VK asked the group about the best way of potentially implementing the proposed change to the incident reporting process that the group had already submitted. The two main options were:
 - Require the DPO, SIRO or equivalent to log in to the IGT and approve the report
 - Have a tick box that the IGT administrator could complete that confirms that the DPO, SIRO or equivalent had been consulted and had approved the incident report being sent.

The group agreed that the second option would be best as it avoids the complication of the DPO, SIRO or equivalent having to have an IGT account which they will seldom be required to use.

Resources that IGT applicants are willing to share to the wider community for the Knowledge Base

- 9 SL reported that so far examples of Information Governance policies had been shared on the JISMAIL list file area and helpful suggestions had been received. SL suggested that providing Knowledge Base exemplars and examples is likely to be an ongoing process and asked whether they could be added as and when ready. VK responded that adding to the Knowledge Base was certainly a separate issue to changes in the requirements and guidance. She thought that as a minimum then there could be two releases per year i.e. at the new version release in June and then the current IGT functionality release in the autumn. It might be possible to add to the Knowledge Base at other times but this would need to be checked with LL. **Action 4.5:** VK to check with LL about frequency of releases to changes in the Knowledge Base.
- 10 SL described how she had to provide her second IGT submission for the NPEU by 9th January following a request from CAG. SL had found the process this time a good and helpful experience and with hindsight could see some of the omissions and difficulties with the first submission which had been “hard work”. VK added that SL’s submission could be seen as an exemplar of how to do it, and virtually everything required had been provided (report score 100%). SL said she was willing to share the submission at least with the Working Group, having redacted any personal information and put in a pdf. **Action 4.6:** SL to share NPEU IGT submission once suitably redacted. SL also noted:
- It had helped that a “friendly” internal audit by Price Waterhouse Coopers just prior to Christmas had been a good preparation as it had been almost identical to the IGT and SL had used the IGT getting ready for the audit.
 - The spreadsheet that VK had circulated to the group had been fantastic and SL had adapted it for local use, added actions etc. (VK noted that the IGT also allows you to download the action plan in Excel format with links and notes all included – but if you make updates then they have to be added directly)
 - One of the areas tightened up this time was confirmation that policies were being monitored i.e. recording that processes were being done.
 - Key documents were both linked and uploaded.
- 11 VK reported that the HSCIC had received a Freedom of Information request on the evidence provided by an NHS Trust for their IGT submission. HSCIC currently considering how to respond balancing their commitment to openness. RM said he could see that it would be an issue for instance if the scanning software an organisation is using was made public. The group noted this development and the potential implications to what gets uploaded.
- 12 VBH said that when the NIHR CRN “Secondary Use Organisation” submission is done in March then she would be happy for this to be shared with the Working Group too once suitably redacted. **Action 4.7:** KBH to share IGT submission once this is made and approved (after the end of March). It was noted that the NIHR CRN Coordinating Centre has asked each clinical research network centre to self-assess using the Hosted Secondary Use Team/Project view and if they are deemed satisfactory by KBH they will be included in the NIHR CRN Coordinating Centres submission.

- 13 JM suggested a key question for the group was how it can help others get to the position SL has achieved with less pain. KBH said there was an element of it always being laborious at the start but that it was useful to go through it. TP shared the support given to groups at UCL now i.e.
- IGT coding different for each research group, but with UCL stem
 - Spreadsheet with paths to individual files
 - TP agrees process with individual research.
 - Data entered in to IGT by the researcher using UCL reference resources and their own
 - TP then meets with researcher to go through submission and finalise
 - Have a data flow risk assessment tool – brought in a specialist for 9 months to set this and other tools up – was able to combine meeting several requirements with one activity e.g. risk assessment tool.
- 14 Following further discussion SL suggested that the Working Group could perhaps provide “training”, rather than a workshop, for those relatively new to the IGT on “How to complete the IGT”. This was agreed as something to pursue, ideally with one session in June and another in November/December as these could then include the changes to the IGT requirements (June) or IGT functionality (Nov/Dec). It was suggested the sessions should be filmed so that they could be an online resource as well. **Action 4.8:** MT to see whether the NHS-HE Forum (funded by Janet) can fund the training sessions. **Action 4.9:** MT to poll dates for the proposed June session. **Action 4.10:** MT to ask Natasha Dunkley at the HRA whether they are willing to be involved/provide support.

The NIHR CRN IGT training package targeted at researchers

- 15 KBH said that the testing was going to plan and the training package should be available within the CRN at the end of January, with the possibility of sharing in mid-February. TP said he was very much looking forward to its release – they are very keen to use it at UCL.
- 16 The training module is hosted by the NIHR CRN and KBH wondered whether hosting by the HSCIC might be possible if usage expanded significantly? VK said that a proposal would have to be put forward. HSCIC had encountered issues themselves with their NHS training tool, currently having to refuse access to researchers wanting to use that because it has no more capacity. TP asked whether a federated model might be considered where the training module can be downloaded as a package on to an organisation’s own servers e.g. in Moodle. This has worked successfully in other areas. **Action 4.11:** KBH would take back to the NIHR whether a federated model might be adopted.

Any other business

- 17 MT had circulated a request from Sam Story at the University of Bristol about the use of scanned documents as a research resource. SL said she had a SOP on this that she would be happy to share. JM suggested the “Grey Guide¹” might help.

Future of Group/Date of next meeting

¹<http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/GoodClinicalPracticeGuide/index.htm> (there is a charge)

- 18 SL suggested that with the proposed approach for incremental changes to the Knowledge Base, proposed changes to the next IGT (v 13) and the proposed training events then the Working Group should continue, and this was supported by the group. The next meeting would be targeted for April to avoid the end of March IGT submission deadline.

Summary of New Actions:

Ref.	Action	Who
4.1	Provide some rewording to incorporate in the final minutes for meeting of 12 th November 2013	VK (done)
4.2	Liaise with Natasha Dunkley at the HRA about use of the letter introducing the Working Group for new s 251 applicants	VK (email sent)
4.3	Circulate the link to the mapping between ISO 27001 versions that is being used by HSCIC.	VK (done)
4.4	Draft proposed change to guidance for requirement 11-223 (All transfers of personal and sensitive information are conducted in a secure and confidential manner) and circulate to the group for comment immediately after the meeting	MT (done)
4.5	Check with LL about frequency of releases to changes in the Knowledge Base (post meeting note – first possible change deadline is 21 st February 2014 at the latest)	VK
4.6	Share recent NPEU IGT submission on JISMAIL file area once suitably redacted	SL
4.7	Share NIHR CRN CC IGT submission once this is made and approved (after the end of March)	KBH
4.8	Check whether the NHS-HE Forum (funded by Janet) can fund the proposed two IGT training sessions (June, Nov/Dec)	MT
4.9	Poll dates for the proposed June training session	MT
4.10	Ask Natasha Dunkley at the HRA whether the HRA might be willing to be involved/provide support for the proposed training sessions.	MT
4.11	Ask colleagues at the NIHR CRN CC whether a federated model might be adopted for wider use of their training module.	KBH