

## NHS HE Information Governance Working Group

### Notes of Meeting on 21<sup>st</sup> November 2014

**Present:**

Andrew Burnham (AB)	University of Leicester
Tito Castillo (TC)	Xperimint Ltd
Peter Dinsdale (PD)	University of Newcastle
Thomas Fleming (TF)	University of Leeds
Kyriakos Hatzaras (KH)	Kings College London
Vanessa Kaliapermall (VK)	HSCIC
Bridget Kenyon (BK, Chair)	UCL
Andrew Lambert	University of Newcastle
Sarah Lawson (SL)	NPEU, University of Oxford
Ravi Miranda (RM)	Institute of Education
Trevor Peacock (TP)	UCL
Lindsay Shure (LS)	UCL
Malcolm Teague (MT)	Janet
Lawrence Thompson (LT)	University of Newcastle
<b>Apologies:</b>	
Athanasios Anastasiou (AA)	University of Swansea
Richard Bartlett	University of Cambridge
Kirsty Benn-Harris (KBH)	NIHR CRN Coordinating Centre
Rebecca Birch (RB)	University of Leeds
Stuart Bloom (SBI)	Independent Consultant
Sally Bridges (SBr)	Health Education Kent Surrey Sussex
Anne Cameron	Kings College London
Wendy Craig (WCr)	University of Newcastle
Will Crocombe (WC)	University of Leeds
Shane Freemantle (SF)	Drug Safety Research Unit
Gearoid Garvey (GG)	Institute of Education
David Golding (DG)	University of Leeds
Barry Haynes	University of Leeds
Gareth Jenkins (GJ)	Cardiff University
Michael Hollis (MH)	Institute of Cancer Research
Anita Kullar (AK)	HSCIC
Janet Messer (JM)	Health Research Authority
Lee Moffatt (LM)	University of Manchester
Debbie Ranger (DR)	University of Warwick
Marion Rosenberg (MR)	London School of Hygiene & Tropical Medicine
Julie Sherrieff (JS)	University of Warwick
Christopher Walker (CW)	University of Leeds
Alyson Williams (AW)	University of Manchester
Hawys Williams (HW)	Nowgen
Adrian Willis (AdW)	University of Warwick
Chris Willis (CW)	University of Sheffield
Tee Wu (TW)	Wolfson Institute, Queen Mary University of London

## Introductions

- 1 BK welcomed everyone especially those attending their first meeting of the group i.e. PD, AL, TF and LT. Everyone briefly explained their role and interest in the work. KH said he was moving jobs and joining a commercial clinical research organisation in January 2015. SL said since the last meeting she has become the IG lead for the Oxford Medical Sciences Division.

## Minutes of the meeting of 13<sup>th</sup> August 2014

- 2 These were agreed as a correct record. There were no matters not on the agenda.

## Update on Actions from previous meetings

- 3 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. Latest update 23/4/14: The proposed change was submitted to HSCIC and it is being considered for future releases (not v12). Wider review action remains carried forward. Update 13/8/14: promised for the next meeting. <b>Update 21/11/14:</b> apologies, carried forward again.
3.1	Letter to be drafted from the Working Group that can be forwarded to appropriate groups registering for the IGT.	BK	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. <b>Action 4.2:</b> VK to liaise with Natasha Dunkley at the HRA about this. Latest update 23/4/14: VK emailed Natasha Dunkley with the proposed letter on 28 <sup>th</sup> January 2014 but as yet there is no response. Not used by HSCIC either until this feedback has been received. <b>Action 6.2:</b> BK to contact Natasha to chase this. Update 13/8/14 – decide that letter can go to IGT applicants anyway and the CAG action to be treated separately. MT to resend the draft letter to VK. <b>Update 21/11/14:</b> MT had reviewed letter and it needs to be updated. SL noted that whatever was happening already as she had been contacted by a number of groups at Oxford and is working with them. MT to amend letter and reissue to VK.
3.2	Provide IGT to ISO 27001 and 27002 mapping for Secondary Use view.	BK	Carried forward in BK's absence. Latest update 19/6/14 – 8 hours of development time needed, will try for next month if possible. Update 13/8/14: BK advised this is now required for another purpose as well so will be looking to complete this in September. <b>Update 21/11/14:</b> BK reported

			that an initial analysis had revealed 200 pages of difference so this will take a while.
4.6	Share recent NPEU IGT submission on JISMAIL file area once suitably redacted	SL	Carried forward. Will aim to do in time for the Training Day on 2 <sup>nd</sup> July. <b>Update 13/8/14:</b> SL said this was nearly done in terms of the redacting and the case study. Also the attendees at the training day really liked the spreadsheet and so planning to share this too. SL asked for volunteers to check over the results – BK volunteered for case study and AB for the redacting etc.
4.7	Share NIHR CRN CC IGT submission once this is made and approved (after the end of March)	KBH	Update 23/4/14: Carried forward as approval not yet official. Latest update 19/6/14: KBH confirmed that this will be available soon for loading on the file area. Update 13/8/14 and <b>Update 21/11/14:</b> Carried forward in KBH's absence.
5.5	Ask for the NIHR CRN Training Package link and circulate to the group. (Also to ask about federated model for access – previously Action 4.11)	MT	See update to 4.11 above – not yet released to wider community. Update 13/8/14: MT to ask KBH for an update. <b>Update 21/11/14:</b> an email update had been received from KBH as follows: “The module will be hosted internally from Jan (however individuals can request access and will be provided this). From April 2015 it will be available via Moodle for anyone to access.”
6.2	Contact Natasha Dunkley to chase up the proposed introductory letter about the Working Group to s251 applicants	BK	<b>Update 21/11/14:</b> Carried forward as for Action 3.1. Once Action 3.1 is done then VK will forward a copy to Natasha.
6.3	Ask Darren Mort to get in touch with BK about the latest on IGT and ISO 27001 mapping.	VK	Carried forward (name recorded wrongly in draft minutes). <b>Update 21/11/14:</b> Darren is the new Security and Risk lead at HSCIC and he is doing work on IGT v13 and the updated ISO 27001 standards. Action carried forward.
6.9	Check whether there is any HSCIC advice on the NIHR collaboration portal	VK	VK reported that there is nothing specific to the NIHR portal but has found some more general information about this kind of portal which she will circulate. Complete.
6.10	Ask HH to be in touch with BK regarding the Janet work with the Farr Institute etc.	MT	Carried forward. Complete. (post-meeting note HH spoke to SL at the NHS-HE Forum)
7.1	Comparison of ECRINS with the IGT.	LS	Carried forward.
7.2	Provide a one page summary on ECRINS to VK so she can explore it further from the	KH	Carried forward.

	HSCIC perspective.		
7.3	Circulate the new statement on ECRIN from the UKCRC	WC	Carried forward.
7.4	Ask for the Working Group to be directly represented by SL at the SIGN meeting on 1st September	VK	Complete. SL attended and is now a member on behalf of the group.
7.5	Ask CAG for the criteria being used to assess the improvement plans.	VK	Carried forward.
7.6	Send the Design Group meeting information on to the Working Group members who volunteered for that i.e. TP and vice LS	VK	The Design Group have met to consider incident reporting. VK will send details to TP and LS.
7.7	Circulate the list of proposed changes in v12.2 once these are available.	VK	Complete. These are readily available on the IGT website.
7.8	Feed in ideas for function or content for v13 for the next meeting.	All	Complete. Nothing received in advance but this is being discussed at the workshop in the afternoon.
7.9	Advise on the date of the key SIGN meeting for review of proposals and then the next Working Group meeting will be set for at least 4 weeks prior to that.	VK	Complete.
7.10	Investigate what incident reporting is possible	VK	Complete, as discussed as a proposed change in the afternoon workshop.
7.11	Send through links on the general update items, plus for subscribing to the "Data Insight" newsletters.	VK	Complete
7.12	Circulate the revised version of the ToR for agreement	MT	Complete
7.13	Draft first version of the marketing document over the next few months	AB	Carried forward (AB has been off sick but now returned)
7.14	Review the NIHR Portal using	KH	Post-meeting note - with KH moving jobs this

	the technology assessment tool in use at KCL.		action is on hold.
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.
7.16	Send details of the “Data Destruction Assurance letter” to VK so she can investigate at HSCIC	LS	Complete as issue has passed. The only issue was who the letter was sent to. VK said it was a letter sent from a different group so difficult to respond. TP and VK agreed to pursue off-line if necessary.

## HSCIC Update

- 4 VK gave an HSCIC update including as follows:
- 5 The new Information Governance “Serious Incident Requiring Investigation (SIRI)” tool went live on 7<sup>th</sup> November. There is an article about it on the [IGT website](#). This implemented an at least interim response to the issue raised by the Working Group where SIRIs could be raised without the responsible Data Protection Officer knowing. VK demonstrated this on the IGT system.
- 6 BK had asked whether there had been any level 2 or above incidents involving research and education organisations since the start of the reporting system in June 2013. VK searched for these on line but could not find any. It was the view of the group that users were unaware of their responsibility to report incidents through the IGT rather than there being no incidents. It was agreed that awareness should be raised on this at the next Training Day. **Action 8.1:** Include incident reporting as a subject for the next training day to raise awareness.
- 7 VK made it clear that it was DH policy that anyone processing health data should have successfully completed an IGT. The question was asked about clinical trials when patient data is collected with the patient’s consent – it is current practice not to seek IGT for that. *[post-meeting note from VK: The IGT in most cases is a pre-requisite for getting connectivity to NHS networks, receiving data from HSCIC through the DAAG/DARS application process, seeking s251 approval from HRA CAG etc. Wording from IGT Standard says completion of annual IGT assessment applies to:*

*All Providers and Commissioners which:*

- *have access to NHS patients and/or to their information;*
  - *provide support services directly to an NHS organisation; or*
  - *have either direct or indirect access to national informatics services, including N3 - the NHS National Network.]*
- 8 A request form for IGT changes for IGT v13 has been published on the website but VK asked that the working group channel their proposals through her so there is one voice from the group. TC asked whether how new groups register has been tightened? VK said that it remains that in a lot of universities individual research groups are doing separate assessments. TC wondered whether asking for DPO approval as part of applying for an IGT assessment would help, as it would indicate that the DPO is aware of the application. SL thought this might lead to delays. VK noted that the current process does prompt for a wider view as it asks whether the

application is separate or part of an institute wide approach. VK said it could be suggested that “talk to your DPO” could be proposed as an addition to the guidance. It was decided to find out the views of DPOs on this. **Action 8.2:** members to ask their DPO about this and report back for next meeting.

- 9 VK reported that there was currently a consultation on an update to the Records Management Code of Practice. It was noted that, for researchers, the approach to records management typically depends on the stakeholder, and funder of the research. It cannot be said that HRA guidance or Records Management Code of Practice is consistently used as the guide. If anyone is interested in this topic area and wants to get further involved in the consultation which runs to the end of January 2015 then they should contact VK.
- 10 The National Information Board has published “[Personalised Health and Social Care for All 2020](#)”. In it says there will be a brand new Information Governance Toolkit by October 2015 – a new platform for information governance in health and social care, and those working with health and social care. In response to this there is a new programme manager appointed, Peter Sharratt, and there are a number of projects over a 2-3 year period, supported by a team of project managers that have been recruited. VK suggested that Peter Sharratt might be invited to a future meeting or training day. The current view was by October 2015 there would be a prototype with a rough scope for consultation on the look and feel, infrastructure and requirements.
- 11 The implications for the usual annual IGT change process was that the next version, v13, due for release in June 2015, for use by the March 2016 IGT deadline, is that the changes should only be for those that are urgent. There will be no major new developments in v13. However when making proposals for change, then looking for those:
  - Urgent for v13, or possibly v14
  - That are more “blue sky” and fundamental towards the new IGT platform
- 12 VK said that the Big Brother Watch report on [NHS Data Breaches](#) had an impact with a [report on the BBC website](#). The detail had been collated between 2011 and 2014 through FOI requests.
- 13 The IG Training Tool is still receiving a lot of requests. Access is still denied for researchers and other external users because of a capacity restraint. It will be part of the new programme to review this.
- 14 There is a current initiative to add cyber security incidents to the incident reporting tool. BK noted that there was not a consistent or well understood definition of “cyber security” so it will need to be defined in the toolkit. BK thanked VK once more for a comprehensive and very useful update.

### **Feedback from the SIGN meetings in September and November**

- 15 SL had attended the Strategic Information Governance Network (SIGN) Chairs Meetings in September and November. SL took the Working Group through a presentation on the key points from the November meeting (post-meeting note – a copy of the presentation, plus the minutes of the meeting, have been circulated). In summary the key points to emerge for SL were:

- The group is lucky to have VK attending (and VK is our link rather than feeding in to SIGN or elsewhere in detail)
  - Certain glow that we are in a similar position to others.
- 16 There was some discussion around the creation of the IG Alliance following the request from the [Independent Information Governance Oversight Panel \(IIGOP\)](#) that there should be one authoritative source of information and guidance for the health and care sector. “The Information Governance Alliance (IGA) is a group of national health and care organisations that are working together to provide a joined up and consistent approach to information governance.” There is more [here](#). The foundation partners and funders are Department of Health, NHS England, HSCIC, Public Health England. Research and education come under “Small Organisations” in the IGA’s groupings, and we should feed in through VK still. The IGA are drawing up plans for engagement with the [Centre of Excellence in Information Sharing](#), a cross-sector organisation, who are going out to areas that are perceived to be not so well controlled in terms of IG e.g. GP practices.
- 17 SL said there was a meeting about Accredited Safe Havens (ASH) the day after the November SIGN meeting. This is a topic of interest to the working group. **Action 8.3:** MT to add “Accredited Safe Havens” to the agenda for the next meeting.

### HSCIC’s Terms and Conditions

- 18 BK had asked for clarification on whether the terms and conditions agreement, which has been sent out for secondary use organisations to sign, really did mean that ISO 27001 could be used as an alternative to the IGT? VK said the question should be submitted to HSCIC DARS/DAAG as this they own the content of the conditions of agreement. IGT is one of 3 options available we believe. However, the requirement to complete an annual IGT still applies within the context of the IGT Standard and DH Policy requirements as stated above in para.7.

### Terms of Reference

- 19 The ToR were updated and agreed at the meeting (post-meeting note, and the final version has been circulated to the Working Group)

### Next Training Day

- 20 It was agreed that the next Training Day/Masterclass should be on 3<sup>rd</sup> February 2015 in London. **Action 8.4:** MT to circulate date to Working Group and to organise venue etc. via Jisc events. It was suggested that there should be one opening session and then break-out sessions, with one stream more for beginners and another for those with experience. VK suggested that in the opening session there it could be explained how the IGT is changing and it would be great if Peter Sharratt could do that. **Action 8.5:** VK to ask Peter Sharratt if he might present to the Training Day on 3<sup>rd</sup> February. There were some who asked to go through a dummy assessment process and this is something SL and VK would be willing to do. VK suggested that it would be good to have a “take home” pack of key information. TC suggested this might include a business process model of how to do the IGT. VK said her colleague John Hodson has done some work on this and will be willing to share and this could be used as a starter. **Action 8.6:** SL to draft a programme for the Training Day. **Action 8.7:** SL to consider a “take home” pack including business process model/flow diagram.

## Feedback to be given to the NHS-HE Forum on 26<sup>th</sup> November

- 21 SL was providing the presentation to the NHS-HE Forum on BK's behalf. It was agreed some of the key messages were around:
- Training Day plan
  - SIGN group and attendance
  - National Information Board strategy
  - IGT next generation
  - Working group members
  - Numbers achieving the IGT
  - ToR update

## Any other business

- 22 TP mentioned that he had experience of different bits of the HSCIC not having access to the list of people on the Working Group and wondered if they could be rectified. This reminded us of the previous work to try and create a list of IGT contacts in each institution. MT said that he only managed to get a few people willing to be on that list but would try again now that more universities are actively involved. **Action 8.8:** MT to try again to create a list of IGT contacts at each institution. **Action 8.9:** VK to consider how existing contacts could be shared with other relevant departments at HSCIC.
- 23 It had been suggested at the last Training Day that a cooperative network of voluntary external auditors might be possible from amongst the community. **Action 8.10:** MT to add "network of external auditors" to the agenda at the next meeting.

## Date of next meeting

- 24 This was agreed for 10.30-13.30 on 8<sup>th</sup> January 2015.

## Workshop on Proposed Changes to the IGT

- 25 VK said that any proposed changes for version 13 would be needed by 15<sup>th</sup> December 2014. Proposals could also be made for a future v14 and anything dramatic or "blue sky" should be put forward for consideration for the new IGT platform and IG Assurance Framework (IGAF2).
- 26 The group reviewed the submissions for v12 that had not been implemented. These were adjusted and agreed for resubmission. A new two proposals were also proposed. **Action 8.11:** MT to send in agreed proposals to VK as soon as possible. (post-meeting note, done on 8<sup>th</sup> December). Any proposed additions to the Knowledge Base would also be needed by 15<sup>th</sup> December 2014.

## Future Requirements

- 27 In discussion the following were proposed as more radical future requirements
- IGT more user friendly with less "clicks"
  - An IGT view which is research related alone. VK noted that some early thinking/ideas is that there could be a move away from "views" but instead there could be core requirements and then a top-up facility for other requirements which may be appropriate dependant on data processing activities, service provision, engagement with



processes/applications etc. There could be, for example, questions at the start which profiles the organisation and the requirements flow from that rather than having rigid views.

- If HSCIC contract would allow ISO 27001 as an alternative, but with recognition that there would have to be guidance that the scope is clearly defined and there are some definite requirements.
- Clarity on approach for Accredited Safe Havens. So far safe havens are assessed through IGT but a different approach might be required.
- Facility to work on IGT off-line and then upload.
- Clarity on the scope of the IGT i.e. for all health and social care data or for s251 requests alone. If wider than s251 then the implications of this need to be worked through.
- Make the attainment levels more upfront, more outcomes based rather than target based.

### Summary of New Actions:

Ref.	Action	Who
8.1	Include incident reporting as a subject for the next training day to raise awareness.	SL
8.2	Members to ask their DPO about whether they would want to be part of the process for instigating a new IGT assessment and report back for next meeting	All
8.3	Add “Accredited Safe Havens” to the agenda for the next meeting	MT
8.4	Circulate date of Training Day to Working Group and to organise venue etc. via Jisc events.	MT
8.5	Ask Peter Sharratt if he might present to the Training Day on 3 <sup>rd</sup> February.	VK
8.6	Draft a programme for the Training Day	SL
8.7	Consider a “take home” pack including business process model/flow diagram for the Training Day	SL
8.8	Try again to create a list of IGT contacts at each institution	MT
8.9	Consider how existing contacts could be shared with other relevant departments at HSCIC	VK
8.10	Add “network of external auditors” to the agenda at the next meeting	MT
8.11	Send in agreed v13 proposals to VK as soon as possible.	MT