

## NHS HE Information Governance Working Group

### Notes of Meeting on 13<sup>th</sup> August 2014

#### Present:

Nigel Bailey	Kings College London
Andrew Burnham (AB)	University of Leicester
Anne Cameron	Kings College London
Will Crocombe (WC)	University of Leeds
Kyriakos Hatzaras (KH)	Kings College London
Barry Haynes	University of Leeds (by teleconference)
Vanessa Kaliapermall (VK)	HSCIC
Bridget Kenyon (BK, Chair)	UCL
Sarah Lawson (SL)	NPEU, University of Oxford
Marion Rosenberg (MR)	London School of Hygiene & Tropical Medicine
Lindsay Shure (LS)	UCL
Malcolm Teague (MT)	Janet
<b>Apologies:</b>	
Athanasios Anastasiou (AA)	University of Swansea
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
Tito Castillo (TC)	University of Cambridge
Wendy Craig (WCr)	University of Newcastle
Peter Dinsdale (PD)	University of Newcastle
Shane Freemantle (SF)	Drug Safety Research Unit
Gearoid Garvey (GG)	Institute of Education
David Golding (DG)	University of Leeds
Michael Hollis (MH)	Institute of Cancer Research
Janet Messer (JM)	Health Research Authority
Lee Moffatt (LM)	University of Manchester
Paul Newton (PN)	HSCIC
Ravi Miranda (RM)	Institute of Education
Trevor Peacock (TP)	UCL
Debbie Ranger (DR)	University of Warwick
Julie Sherriff (JS)	University of Warwick
Christopher Walker (CW)	University of Leeds
Alyson Williams (AW)	University of Manchester
Hawys Williams (HW)	Nowgen
Chris Willis (CW)	University of Sheffield
Tee Wu (TW)	Wolfson Institute, Queen Mary University of London

#### Minutes of the meeting of 19<sup>th</sup> June 2014

- 1 These were agreed (except later noted that a name was recorded wrong – will be updated and added to the website).

**Update on Actions from previous meetings**

- 2 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. <b>Update 13/8/14:</b> promised for the next meeting.
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”. Latest update 23/4/14: no news yet, carried forward. Latest update 19/6/14: there has not been another meeting. <b>Action 6.1:</b> VK will find out the date of the next meeting. This action “closed” because the IGT Editorial Board does not exist any longer. See HSCIC update for more information on what will replace it.
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. <b>Update 13/8/14</b> – 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.
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. <b>Update 13/8/14:</b> BK advised this is now required for another purpose as well so will be looking to complete this in September.
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. Latest update 19/6/14: BK to ask TC. Action closed – incorporated in to Action 3.2 if required.
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. <b>Action 4.3:</b> 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. Latest update 19/6/14: VK said that Darren Mort at HSCIC had done work on this. <b>Action 6.3:</b> VK to ask Darren Mort to get in touch with BK. Action 3.4 closed – overtaken by other developments.
4.2	Liaise with Natasha Dunkley at the HRA about use of the letter introducing the Working Group for new s 251 applicants	VK	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. Latest update 19/6/14: BK to chase Natasha, same action as for 3.1. Action closed as replaced by 6.2.
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. <b>Update 13/8/14:</b> Carried forward in KBH's absence.
4.11	Ask colleagues at the NIHR CRN CC whether a federated model might be adopted for wider use of their training module.	KBH	Latest update 19/6/14: NIHR have a new Learning Management System based on Moodle. KBH has asked why the IG training is not yet public and has been told that this will be available next week. Any federated access would need to be negotiated. <b>Update 13/8/14:</b> Action merged with 5.5. Closed.
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. <b>Update 13/8/14:</b> MT to ask KBH for an update.
6.1	Find out the date of the next meeting of the IGT Editorial Board	VK	Closed – IGT Editorial Board is being replaced.

6.2	Contact Natasha Dunkley to chase up the proposed introductory letter about the Working Group to s251 applicants	BK	Carried forward
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)
6.4	Speak with Steve Canham to find out more about any overlap between ECRIN and the IGT	KH	Complete in that KH had been in touch with Steve Canham. His initial advice in summary was that there is probably not too much of an overlap and that ECRINS and the IGT are complementary. However after a wide ranging discussion it was agreed that that it does need to be kept on the agenda to monitor developments e.g. if UK adoption was agreed. <b>Action 7.1:</b> LS volunteered to help with comparison of ECRINS and the IGT. <b>Action 7.2:</b> KH to provide a one page summary to VK so she can explore further from the HSCIC perspective. <b>Action 7.3:</b> WC to circulate the new statement on ECRIN from the UKCRC.
6.5	Email out to IGT administrators and make an announcement on the IGT news page (post meeting note – email done, decided not to pursue website notice)	VK	Complete. Very helpful. Although this was done close to the Training Day it did encourage attendance by a number of attendees not previously known by the Working Group.
6.6	Revise and circulate the Terms of Reference for the next meeting.	MT	Complete. Revision on the agenda.
6.7	Members to offer up some of the things they have for potential inclusion in the Knowledge Base.	All	Closed. SL working now with what has already been submitted for the end of August deadline.
6.8	Liaise on the NIHR collaboration portal assessment	KH and KBH	Closed. NIHR portal on the agenda and will be taken forward from that.
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.
6.10	Ask HH to be in touch with BK regarding the Janet work	MT	Carried forward.

## HSCIC Update

- 3 VK gave an HSCIC update including as follows:
- 4 The IGT Editorial Board has been disbanded and a lot has been happening on setting up wider Information Governance networks. The new Strategic Information Governance Network (SIGN) group is holding an initial shaping meeting on 1<sup>st</sup> September. BK asked that the Working Group is represented at that meeting if at all possible (SL is available in BK's absence). **Action 7.4:** VK to ask for the Working Group to be directly represented by SL at the SIGN meeting on 1<sup>st</sup> September.
- 5 HSCIC have received a request from CAG to provide the IGT improvements plans from s251 applicants. So these are now being sent through. **Action 7.5:** VK to ask CAG for the criteria being used to assess the improvement plans.
- 6 IGT v12.2 will be for functional changes and this is mainly going to be around the reporting tool following consultation with the Design Group. There is a Design Group meeting in September. **Action 7.6:** VK will send the Design Group meeting information on to the Working Group members who volunteered for that i.e. TP and vice LS. It is planned that v12.2 will include the incident reporting changes previously discussed by the group. WC said that it would be useful to have a comments box next to each item so that reviewers can easily respond and feedback can more easily be collated. VK said this could be done using the download facility but perhaps this needs to be made clearer. **Action 7.7:** VK to circulate the list of proposed changes in v12.2 once these are available.
- 7 The review work for IGT v13 is starting early i.e. Sept/Oct. The group needs to aim to provide any proposals in December. It was agreed that like last time there would be one consolidated list sent from the Working Group and that we would concentrate on areas where members thought there was an issue, plus a review of those proposals deferred from last time. **Action 7.8:** Everyone to feed in ideas for function or content for v13 for the next meeting. VK said that the agreed proposal will go to the SIGN group and they will need it 4 weeks before their meeting. **Action 7.9:** VK to 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.
- 8 There is a new project on cyber security incident reporting following a formal commission from the Department of Health. Looking at impact and will be looking to enhance systems already in place. BK asked whether there was any idea of the numbers of incidents at each severity level, ideally on our sector. How many were referred to the ICO would also be useful and categorisation by type of incident. It was also suggested that incidents that are closed should be published. **Action 7.10:** VK would investigate what incident reporting is possible.
- 9 VK reported there was nothing new on the Public Services Network compliance comparison with IGT work, or from the cyber security group. VK then went on to brief the group on a number of other IG related activities at HSCIC, such as:
  - New request process for data requests
  - The latest on care.data
  - NHS England technology strategy

- A “Code of Practice on Confidential Information” has been drafted and will be shared as soon as in the public domain. This was requested of the HSCIC as part of the Health and Social Care Act and it follows on from the guide that was published last year.

**Action 7.11:** VK to send through links on these items, plus for subscribing to the “Data Insight” newsletters.

10 BK thanked VK for once more for an excellent update.

### **Terms of Reference**

11 The draft revised terms of reference were discussed and various further suggestions made.  
**Action 7.12:** MT to circulate the revised version for agreement. It was later discussed that the Terms of Reference might need a more fundamental revision with a more generic aim of “improving information governance in the clinical research and education community” or similar and this will be discussed further next time.

### **Membership**

12 The membership was discussed. AC made the point that it was possibly “IT heavy” and there were not many representatives from for instance Data Protection Officers or Finance. SL said that the way it works at Oxford is that she liaises with others locally from other disciplines. However if others wanted to join to strengthen input from these other areas then that would be encouraged.

### **Training Day on 2<sup>nd</sup> July**

13 The feedback (as circulated) for this event was very positive and BK thanked everyone who contributed to such a successful day.

### **Another Training Day?**

14 It was agreed the aim should be to repeat it next year at a similar time. The “expert panel” and workshop approach had been particularly effective and popular so we would look to build on that. Also it was suggested that case studies could be presented on areas that were found to be the difficult ones.

15 It was also suggested that there might be a need for a follow-up training event this round when groups are most actively trying to complete their IGT. There was a danger of “doing the IGT for them” which would undermine its value but following discussion it was agreed that a “masterclass” format say in the third week of January should be investigated. It was thought that general overviews would be kept to a minimum with the focus on going through the IGT sections in detail, possibly grouped on the type of institution. Dummy accounts for the IGT would be very helpful. SL, VC and BK volunteered to be involved and it was hoped that TP might volunteer too (in his absence!). Ideally there might be 3 from HSCIC to assist. This to be discussed more fully at the next meeting.

### **Proposals for the Knowledge Base**

- 16 The deadline for proposed updates to the Knowledge Base was the end of August. SL said she was close to having a proposal ready for review. BK agreed to have a first review if required.

**Potential Marketing document to raise awareness in HE about the issues**

- 17 It was agreed that this would be valuable e.g. from some of the issues raised from some Universities as part of the Training day. AB kindly volunteered to have a go at a first draft.  
**Action 7.13:** AB to draft first version of the marketing document over the next few months.

**Google cloud-based NIHR collaboration portal**

- 18 KH introduced the technical assessment method they use at KCL to appraise any technological development. They have for instance reviewed four systems for file sharing (and one looks good from this). KH volunteered to apply this assessment to the NIHR portal. **Action 7.14:** KH to review the NIHR Portal using the technology assessment tool in use at KCL.

**Any other business**

- 19 WC said he has looked through IGT version 12 and his impression was that there was nothing too frightening in there.
- 20 VK said that in HSCIC they produce overview action plans setting out the different things a group was looking at doing. It was agreed that this could be applied to the IG working group to set out an overall programme. **Action 7.15:** VK to provide an example action Plan and MT to have a first go of doing this for the Working Group.
- 21 AC raised the “Data Destruction Assurance letter” which KCL had received and presumably others. It had caused some confusion, not least in terms of who it had been addressed to. LS had experience of this for his project area at UCL. **Action 7.16:** LS to send details of the letter to VK so she can investigate at HSCIC.

**Date of next meeting**

- 22 This would be arranged for 4 weeks prior to the key SIGN meeting mentioned by VK (later agreed that working group would meet on 21<sup>st</sup> November 2014).

**Summary of New Actions:**

Ref.	Action	Who
7.1	Comparison of ECRINS with the IGT.	LS
7.2	Provide a one page summary on ECRINS to VK so she can explore it further from the HSCIC perspective.	KH
7.3	Circulate the new statement on ECRIN from the UKCRC	WC
7.4	Ask for the Working Group to be directly represented by SL at the SIGN meeting on 1st September	VK

7.5	Ask CAG for the criteria being used to assess the improvement plans.	VK
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
7.7	Circulate the list of proposed changes in v12.2 once these are available.	VK
7.8	Feed in ideas for function or content for v13 for the next meeting.	All
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
7.10	Investigate what incident reporting is possible	VK
7.11	Send through links on the general update items, plus for subscribing to the "Data Insight" newsletters.	VK
7.12	Circulate the revised version of the ToR for agreement	MT
7.13	Draft first version of the marketing document over the next few months	AB
7.14	Review the NIHR Portal using the technology assessment tool in use at KCL.	KH
7.15	Provide an example action Plan and MT to have a first go of doing this for the Working Group.	VK/MT
7.16	Send details of the "Data Destruction Assurance letter" to VK so she can investigate at HSCIC	LS