NHS HE Information Governance Working Group

Notes of Meeting on 15th October 2015

Present:

Richard Bartlett (RB)	University of Cambridge
Andrew Burnham (AB)	University of Leicester
Tom Chan (TC)	University of Surrey
Wendy Craig (WeC)	University of Newcastle, by teleconference
Will Crocombe (WiC)	University of Leeds
Gearoid Garvey (GG)	Institute of Education, UCL
Stewart Doyle (SD)	University of Hull
Natasha Dunkley (ND)	HRA
David Evans (DE)	HSCIC
Tom Fleming (TF)	University of Leeds, by teleconference
Susan Graham (SG)	University of Edinburgh, by teleconference
John Hodson (JH)	HSCIC
Mia Kalezic (MK)	QMUL
Bridget Kenyon (BK, Chair)	UCL
Anthony Lambert (AL)	University of Newcastle, by teleconference
Trevor Peacock (TP)	UCL
Jethro Perkins (JP)	LSE
Flavius Plesu (FP)	University of West London
Marion Rosenberg (MR)	LSHTM
Estelle Spence (ES)	HSCIC
Malcolm Teague (MT)	Jisc
Julian Vinnels (JV)	University of Exeter, by teleconference
Graeme Wolfe (GW)	University of Westminster
Peter Wood (PW)	Institute of Cancer Research
Arouna Woukeu (AW)	QMUL
Apologies:	
All other group members	

Minutes of the meeting of 15th May 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 action that were closed were:

Ref.	Action	Who	Update
5.5	Ask for the NIHR CRN Training Package link and circulate to the group. (Also to ask about federated model for access –	MT	Update 21/11/14: 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

	previously Action 4.11)		provided this). From April 2015 it will be available via Moodle for anyone to access." **Update 15/05/15**: TP has been in touch with them and has a contact that he will pass to MT to follow-up (post-meeting note – done). **Update 15/10/15**: A link to the training package had been circulated to the Working Group but on the basis that there is no support available for user issues from NIHRCC. There was an offer of the package being hosted elsewhere for wider use. There was then a question of whether it will be possible for updates to be made and if so who would agree them. JH said that HSCIC were also updating their IG course at present (but if you have done the current one, no need to redo this year). **Action 11.1**: more detailed discussion on the way forward with the NIHRCC course to be on the agenda for the next meeting.
7.5	Ask CAG for the criteria being used to assess the improvement plans.	VK	Update 8/1/15: JH said that he had a conversation with Natasha Dunkley about this but did not have an answer to give today. Update 15/05/15: VK had met with Natasha and Mark Taylor. Nothing to report at present, awaiting developments. **Update 15/10/15**: ND reported that CAG will not be routinely carrying out any assessments of improvement plans (although reserve the right to intervene on big applications which are thought to be weak). Closed.
8.9	Consider how existing contacts could be shared with other relevant departments at HSCIC	VK	Ongoing. Update 15/05/15: It is hoped that HSCIC framework contacts can become part of the group so possibly review that later. **Update 15/10/15:** Closed now that HSCIC sections are invited to the Working Group.

HSCIC IGT/IGAF2 Update

3 JH reported that following the feedback from the workshop held with the Working Group back in May, it had been decided to exclude the Secondary Use Organisation and Hosted Secondary Use Team/Project from the development of the toolkit with the simplified interface. This had gone live in September and is aimed at small scale users such as general and dental practices.

4 Any suggested changes for v14 are needed for January 2016 so the deadline for any changes from the group is before Christmas. Again it will be tweaks rather than wholesale changes. BK said there were suggestions made previously that could be reviewed again. JH did say it was now

possible to change the wording for different target groups which is a move on from previous editions.

5   As the group know Dame Fiona Caldicott, the National Data Guardian, to "contribute to a [review of standards of data security](#) for patients' confidential data to be carried out by the Care Quality Commission (CQC). Dame Fiona will contribute to this review by developing clear standards for the protection of personal data against which every NHS provider organisation will be held to account. The work will be completed in January with recommendations on how the new standards can be assured through CQC inspections and NHS England commissioning. She is also considering how these may be applied in social care." JH said this has impacted on the IGT development in two ways:

- IGT development and resource has been allocated to implement the recommendations in to IGT v14.
- Dame Fiona was presented with the alpha version of the IGT. Her review group are conscious of the burden on the NHS of any major changes.

6   JH did indicate that some of the issues mentioned by the review group included the need for more training and the physical storage of paper notes – e.g. left on trolleys, or in vacant buildings.

Update on position with HSCIC Framework Agreement

7   DE announced that, as promised some time ago, there was to be a public review of the Framework Agreement and Data Sharing Agreements and there was a consultation live on the website. Responses are requested by 30th October.

8   The Working Group noted that it had already supplied its thoughts on the framework agreement and it was agreed that the group would convert that to a submission from the group as a whole and then each University, research institution or research group would be encouraged to respond individually as well, making any different points plus emphasising those from the group which particularly affected them. **Action 11.2**: MT to recirculate the proposed changes to the framework agreement previously agreed, and to incorporate them in to the draft response from the group.

9   WC said that she had been through the questionnaire and it goes through the individual clauses. Newcastle will be putting in a University submission next week. WC asked what happensabout the different versions of clauses that are in existence? DE advised to respond against the version of the clause on the website.

10   It was asked whether it was possible to include on a website all the different versions of the Framework Agreement that have ever been signed? DE said the majority of different versions had been based on changes to the liability provisions and similar. He did not think it was possible to publish in this way.

11   It was asked whether it was likely that the assurance options would be restricted to IGT or ISO27001 next year. DE said that nothing had been confirmed but that was the way the discussions were moving. It was noted that 3 year contracts could be agreed with IGT or ISO27001 as the assurance, otherwise only 1 year was available.

HSCIC Data Dissemination Service Update

12   ES was welcomed to her first meeting. ES explained that she was attending on behalf of Terry Hill who is the Data Dissemination Director at HSCIC. There is a recently set up Data Access Request Service (DARS) Customer Improvement Working Group which met for the first time on 21st September. Members have been drawn from responses to an invitation to every contract signatory and then cut down to 27 overall. There are four subgroups:

- Application Acceptance Process
- Guidance Materials
- Online application process
- Website

13   BK asked 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 a coordinated view of all applications? **Action 11.3**: ES will check that this has been requested. There was also interest in who was representing research and education on these groups and, **Action 11.4**, ES said she would circulate the list of those involved.

HRA Update

14   ND reported that the UKCRC R&D Forum had met a few weeks previously and the issues with HSCIC data flows had been discussed, with an speaker able to give an example of the impact on research.

15   The HRA Approval IG work stream have held a number of positive workshops and the final session was about a fortnight ago. The questions have been revised and they are now looking at the assessment criteria. Outputs expected at the end of the year.

16   The Memorandum of Understanding with NHS Wales has been signed after 18 months of negotiation and delay. There now needs to be an approval process put in place, one has been suggested but not yet confirmed.

SIGN Meetings

17   TP had attended the last two meetings on behalf of BK. They are mostly NHS focused but TP said there were a couple of important things to report:

- The creation of CareCERT as a proactive security incident response team for health and social care. It was noted that this was similar to the CSIRT run by Jisc for the UK research and education community.
- The further development of the Information Governance Alliance (IGA) as the "single source of IG truth" for health and social care. It is currently hosted by HSCIC but is planning to be a separate organisation, possibly a professional body in the longer term. It is trying to provide as much clarity as possible. It has provided webinars and there is some guidance on the website, including guidance to Trusts on the use of honorary contracts. **Action 11.5**: JH will circulate the link for the IGA guidance on honorary contracts.

Updates from Members

18   The following updates were given:

- GG for UCL IoE – had met with Gary Coleman of HSCIC and did a review of a longitudinal study. A very useful conversation.
- MR for LSHTM – meeting in the New Year to decide what is required for next steps.
- JP for LSE – just submitted the Framework Agreement. For next time planning to take the ISO27001 approach with limited scope, and using IGT as source of controls. Going out to the Schools and IT Committee to agree the way forward.
- GW for University of Westminster – finalising details on the Framework Agreement, getting there. Probably looking to IGT rather than ISO27001. Proposing to sign at Faculty level. Been useful to get experience from others.
- AB for University of Leicester – AB has been seconded from IT to the College of Medicine to lead on IG, including to develop a University IG strategy. There has been a growing awareness of risk which is a positive thing. Can now influence some of the IT developments to ensure IG more built in.
- QMUL – MK and AW reported. AW – slightly different approach at QMUL with different departments doing this. 3 or 4 have the IGT, but need to include central IT as they hold the data etc. Several senior meetings have been held and hoping to find resources to look at IG at an organisational level. Framework contract has been signed, for a year. In terms of MK's unit – about to apply for level 3. MK works in a different unit but is aware of what is happening with central IT services. Her unit initially had 100% level 3 but with assessment there were some drops from 3 to 2 and currently at 71%.
- SD for University of Hull – signed the framework agreement, some issues. Hull quite new to this but the Registrar has become the SIRO and an information assurance programme has been created.
- TC for University of Surrey –in the process of signing the framework agreement, relating to one department. Looking for a more coordinated approach for the university through a project on this. Some difficulties experienced with consent.
- RB for University of Cambridge – in year 3 of using the IGT. Complicated because also have a local data sharing agreement with the NHS Trust. IG support has recently been centralised, 3 people including 1 ex-NHS.
- TP for UCL – full-time on IG but not enough hours in the day. Moving towards a single IGT for the Safe Haven, as core covering 80% of governance. Doing v13 for this. Individual studies will complete the subset outside this. As time goes on, pensioning off some of the old IGTs e.g. where 2 IGTs for one research group, so merging down to fewer. Still some departments that cannot use the Data Safe Haven so will remain outside this approach.
- WC for University of Leeds – been audited by HSCIC recently. Have had some difficulties with a long term study where patient consent was from 10 years ago. Have stopped getting the data and missed a year of follow-up for the research for the Lancet. Talked to ES and Gary Coleman and as can't go back to the patients have put a notice on the website with the details of the study and what is proposed. Going back to DARs in September on this.
- PW for ICR – in third year of submission. Currently level 2 but working towards level 3. Getting more resource in IG.
- JV for University of Exeter – a security policy has been developed for one of our projects but want to think wider. IG resource was lost in a recent large restructuring. A discussion paper has been developed, with a proposed move to IGT submission or submissions

- WC for University of Newcastle – IG project started in earnest in August. WC has been seconded to work on this. The first meeting of the steering group has been held, chaired by the Associate Dean of the Medical School. The framework agreement has been signed using the "other assurance" box. No IGTs yet, hoping to start submissions from January. Interested in the "single toolkit" approach at UCL and will contact TP.
- SG for University of Edinburgh – running a project to create a series of template documents for completing the IGT. Individual research groups will apply but will be encouraged to use the standard documentation.

HSCIC Audit

19   DE is the IG lead auditor and was recently involved in the University of Leeds audit which he thought had gone well! WC agreed and it was especially interesting as the audit was on a project outside his direct remit and on a group without an IGT. There were some learning points.

20   There were planned to be 25 audits by 25th March 2016, and 30 per year thereafter. Either high or low IGT scores could trigger an audit, or asking for a lot of data, or high or low incident reports. Usually 2 weeks' notice but could be immediate if "major non-conformity" reported.

Training Day

21   It was still planned to hold another Training Day in January or early February. **Action 11.6**: MT to pursue arrangements

Date of next meeting

22   To be agreed.

Summary of Open and New Actions:

Open actions:

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.
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.
6.2	Contact Natasha Dunkley to chase up the proposed introductory letter about the Working Group to s251	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

	applicants		agreed.
7.1	Comparison of ECRINS with the IGT.	LS	**Update 15/10/15:** Carried forward in LSs absence.
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.
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 15/10/15:** Carried forward.
8.8	Try again to create a list of IGT contacts at each institution	MT	Carried forward. Update 15/05/15: Suggested an extra column is shown that indicates whether 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.
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.
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.

New Actions:

Ref.	Action	Who
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
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
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

11.4	To circulate a list of those representing research and education on the DARS subgroups.	ES
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