

NHS HE Information Governance Working Group

Notes of Meeting on 23rd April 2014

Present:

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

Introduction

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

HSCIC Update

- 2 VK updated the group as follows:
 - ICT v12 update – authoring complete. A test site is under preparation for user acceptance testing, expected mid-late May. Looking for user acceptance volunteers
Action 5.1: let VK know if anyone would like to volunteer for user acceptance testing of v12.
 - There could be some last minute changes to v12 because of cyber security implications.
 - There are some ISO27001 references in v12 but more expected in v13.
 - Caldicott2 implications have been included.

- Currently working on a change log to go to the new Board for approval – the Standardisation Committee for Care Information¹ (SCCI) which has taken over from the Information Standards Board (ISB). The plan is that all the changes will go through as one submission.
 - The new version of the IGT guidance is at near final draft. Scotland and Wales have asked for exceptions on the basis of equivalent processes (Scotland are expected to publish their process end of April/beginning of May).
 - Toolkit submissions deadline from the NHS was at end of March so have been very busy. There is a helpdesk backlog being cleared at the moment. Reports requested on IGT from Care Quality Commission and Office of the Information Commissioner. Tables of level achieved for each requirement produced, although not a Hosted Secondary Use Team/Project view yet. These tables will be published on the website later.
 - There are 186 registrations for the Hosted Secondary Use Team/Project view and 90 of these published by 31st March 14 for v1.1. However 31st March is not a hard deadline for CAG. Of the 96 that have not published, 60 are believed to be active and 36 inactive i.e. not responding to communications.
 - An analysis of the 90 Hosted Secondary Use Team/Project view publications has been made for the Cabinet Office. 85 out of the 90 achieved Level 2+. They were particularly interested in the requirements around contracts (the 100's) and security (the 300's). All Hosted Secondary Use Team/Project view applications are all reviewed by HSCIC so the assessments of the levels should be sound.
 - HSCIC team resources, since the last meeting:
 - Information and Security Risk Manager in post
 - Records Manager & Quality Manager in post
 - Replacement Project Manager in place (Anita Kullar replacing Lucy Lucas)
 - Advert for Senior Business Analyst going out on 30th April
 - Helpdesk queries – peak season so bit of a backlog – 1000 or so. Working through them as fast as possible.
 - A lot going on with the fall-out from the care.data public debate and pause to the implantation. **Action 5.2:** VK will circulate any briefing statements that are available from HSCIC on care.data.
- 3 From the following discussion VK mentioned that it is DH policy that the IGT is required for any handling of NHS data, not just s251 requests. SL said it wasn't something research groups were doing for NHS data where there was patient consent, and this would be a significant change to what currently happens. **Action 5.3:** VK will find the related guidance and circulate to the group.
- 4 VK said there is some concern about the volume of research & education IGT registrations and HSCIC are interested in any ways that the number can be reduced e.g. using the coordinated approach like UCL. SL said that she had visited TP and seen the UCL functionality. It is very good but some Universities like Oxford do not have a centralised approach. AB described the lack of a formal and coordinated approach at his University. It was agreed that the UCL tools should feature in the training day. Also the action to find out which approach each University is taking will be revitalised. It is hoped the Training Day will help with this.

¹ <http://www.england.nhs.uk/iscg/scci/>

- 5 VK asked whether any standards are missing. SL wondered whether the European Clinical Research Infrastructures Network [ECRIN](#) (project) would have an impact as it goes in to quite a lot of detail on for instance how data is stored. SL thinks WC has been involved. **Action 5.4:** ask WC about potential impact of ECRIN on the IGT.
- 6 VK said that currently Public Health departments are typically using the Hosted Secondary Use Team/Project view alongside HE, but that they are housed in Local Authorities now and there is an updated Local Authority view. The expectation is that Public Health Departments will be increasingly covered by the wider LA view submissions.

Minutes of the meeting of 24th January 2014

- 7 These were agreed.

Update on Actions from previous meeting

- 8 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 carried forward.
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. Latest update 23/4/14: Given the mechanism to be included in version 12 it was agreed this action was no longer necessary. Closed.
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.
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. Latest update 23/4/14: VK emailed Natasha Dunkley with the proposed letter on 28 th January 2014 but as yet there is no response. Not used by HSCIC either until this feedback has been received.

3.2	Provide IGT to ISO 27001 and 27002 mapping for Secondary Use view.	BK	Carried forward in BK's absence.
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 23/4/14: carried forward in BK's absence.
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. Latest update 23/4/14: carried forward in BK's absence.
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. This was circulated. Complete.
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. Latest update 23/4/14: JM reported prior to the meeting that the funding request was successful so this HRA project can be covered at future meetings. Complete.
4.2	Liaise with Natasha Dunkley at the HRA about use of the	VK (email	Latest update 23/4/14: VK emailed Natasha Dunkley with the proposed letter on 28 th January

	letter introducing the Working Group for new s 251 applicants	sent)	2014 but as yet there is no response.
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	VK had checked with LL and the preference was that Knowledge Base changes are made at a formal release. There is an expected release 12.2 in October and any proposed changes would be needed 6-8 weeks before that i.e. around August. This action complete, follow-up Action 5.1: VK to clarify deadline for Knowledge Base proposed changes for 12.2 release.
4.6	Share recent NPEU IGT submission on JISMAIL file area once suitably redacted	SL	Carried forward.
4.7	Share NIHR CRN CC IGT submission once this is made and approved (after the end of March)	KBH	Carried forward as approval not yet official.
4.8	Check whether the NHS-HE Forum (funded by Janet) can fund the proposed two IGT training sessions (June, Nov/Dec)	MT	MT confirmed that venues and refreshments can be funded by the NHS-HE Forum & Janet. Complete.
4.9	Poll dates for the proposed June training session	MT	Carried forward until there is proposed programme for the training day so know who has to be available. On the agenda.
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	Email recently sent to Natasha (post meeting note – Natasha has kindly agreed to take part, so Complete)
4.11	Ask colleagues at the NIHR CRN CC whether a federated model might be adopted for wider use of their training module.	KBH	Carried forward in KBH's absence.

The NIHR Training Package

- 9 KBH was not present but had briefed MT that the package was now available from the NIHR CRN Learning Management System. **Action 5.5:** MT will ask for the link and circulate to the

group. VK noted that due to the pressure on the HSCIC IG training module it is unlikely that Universities will be able to register to use it, so the NIHR CRN package is particularly timely.

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

- 10 SL reported that redacted examples were in progress. She encouraged submission of more examples to be sent to her. The next opportunity for adding to the Knowledge Base is in version 12.2 in October but this means the proposed changes are needed in August. This will need to be the focus of the next meeting.

Proposed Training Days in July and November

- 11 The purpose and outline of the day in early July was discussed. SL agreed to draft a programme that can then be worked on further. **Action 5.6:** SL to draft a proposed programme for the July training day (post meeting note – done). The day will be positive about the IGT as an enabler of research, not a gripe session. It will be aimed at those new to the IGT as well as those with experience. Volunteers from the Working Group would be very helpful, if not speaking then assisting with breakout sessions.
- 12 The CAG would be asked to advertise this through their list of contacts and VK said it should be possible to do this through the toolkit too. **Action 5.7:** MT to ask Natasha Dunkley to advertise the training day through CAG contacts.

Future of Group/Date of next meeting

- 13 Everyone agreed that the Group should continue and the terms of reference will need to be updated at the next meeting.
- 14 Next meeting in mid-June (now agreed as 19th June)

Summary of New Actions:

Ref.	Action	Who
5.1	Let VK know if anyone would like to volunteer for user acceptance testing of v12. (post meeting note – RM and GG volunteered)	All
5.2	Circulate any briefing statements that are available from HSCIC on care.data.	VK
5.3	Find the guidance on the scope of the IGT in terms of wider NHS data and circulate to the group.	VK
5.4	Ask WC about potential impact of ECRIN on the IGT	MT
5.5	Ask for the NIHR CRN Training Package link and circulate to the group.	MT
5.6	SL to draft a proposed programme for the July training day	SL (done)
5.7	Ask Natasha Dunkley to advertise the training day through CAG contacts	MT