

## NHS HE Information Governance Working Group

### Notes of Meeting on 29<sup>th</sup> January 2018

#### Present:

Alex Bailey (AB)	MRC/University of Edinburgh, by teleconference
Richard Bartlett (RB)	University of Cambridge
Andrew Burnham (AB)	University of Leicester
Tim Chater (TiC)	University of Sheffield
Robert Churm (RC)	St Georges, UoL
Gerry Collins (GC)	QMUL
Wendy Craig (WeC)	University of Newcastle, by teleconference
Will Crocombe (WiC)	RISG Consulting
Simon Crouch (SC)	University of York
Bill Davidson (BD)	Health Research Authority
Claire Edgeworth (CE)	Institute of Cancer Research
Gearoid Garvey (GG)	UCL
Carlotta Greci (CG)	The Health Foundation
Emily Griffiths (EG)	University of Manchester, by teleconference
Chris Hall (CH)	KCL, by teleconference
Barry Haynes (BH)	University of Leeds, by teleconference
John Hodson (JH)	NHS Digital
Mia Kalezic (MK)	QMUL
Rebecca Lowe (RL)	University of Manchester, by teleconference
Mary McDerby (MM)	University of Manchester, by teleconference
Mark Packer (MP)	Brighton Sussex Medical School
Marion Rosenberg (MR)	London School of Tropical Medicine and Hygiene
Lindsay Shure (LS)	Shuresecure Ltd
Malcolm Teague (MT)	Jisc
Richard Welpton (RW)	Cancer Research UK
Arne Wolfson (AW)	The Health Foundation
Haiyan Wu (HW)	Public Health England, by teleconference
Tee Wu (TW)	QMUL, by teleconference
<b>Apologies:</b>	
All other group members	

#### Minutes of the meeting of 4<sup>th</sup> July 2017

- 1 These were agreed.

#### Update on Actions from previous meetings

- 2 It was agreed that under the new Chair, WeC, and because many have languished for a while, the Group would start afresh with a new action list from this meeting onwards.

#### Terms of Reference review

- 3 The current terms of reference had been circulated. WeC suggested these would be considered again at the next meeting.

### **Data Security Protection Toolkit Update for HE**

- 4 JH gave an update on the development of the Data Security Protection Toolkit, with emphasis on how it will apply to Group members. A copy of this presentation was circulated to all members.
- 5 Members felt it was important that there was one process covering DARS and the Toolkit for data requests. JH said Martin Severs has received that message directly too. DARS will be able to access the Toolkits, but DARS may well always need higher assurance.
- 6 It was agreed that DARS needed to be involved in the Working Group and this would be something to work on further.
- 7 Those submitting IGT 14.1 submissions for 2017/18 financial year (by April), will receive details of how to register for the new system.
- 8 The website will be <https://www.dsptoolkit.nhs.uk/> (post meeting note: now live)
- 9 JH has a spreadsheet of DSPT v4.2 assertions (evidence items) and he will circulate to the group for comment, plus ask a few questions (circulated by WeC 30<sup>th</sup> January)
- 10 It was also agreed that group members would share DARS requests for extra requirements and also copies of answers provided.

### **NHS Digital Update – External IG Team**

- 11 Magi Nwoli at NHS Digital has moved on from the External Information Governance team but has supplied an update report on IGT submissions from the research community. This has been circulated prior to the meeting.

### **HRA Update**

- 12 BD gave an update on the work that has been done with partner organisations and volunteers from the research community to produce guidance on GDPR and health research. Three members of the Working Group contributed to the group that worked on this, and the draft guidance was published on 20<sup>th</sup> December 2017. It was based on best endeavours in the absence of definitive guidance from the EU and ICO and it predates the UK law required to give effect. As it happened the EU produced guidance on the same day but as there was nothing inconsistent the group published anyway, on the HRA website (there have been some recent updates<sup>1</sup>). It is aimed at IG staff, will be looking to create more operational guidance later.
- 13 The main message is that in GDPR there are different legal bases by which to process data, and some are little different to current arrangements. It is recommended that “Consent” is not used as a legal basis under GDPR as this generates a series of rights, which if exercised, could

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<sup>1</sup> See <https://www.hra.nhs.uk/about-us/news-updates/gdpr-guidance-updated-new-law-approaches/>

compromise the viability of the research. Consent is still needed under common law but the better bases for GDPR purposes depends on the type of organisation:

- Public authorities like NHS Trusts or Universities – “Legitimate Interest”
- Charities etc. – “Other Legal Activity”

- 14 BD also raised the issue of the Confidentiality Advisory Committee only accepting an IGT score. This doesn't fit well with others outside England and those using ISO 27001. HRA is working on a high level agreement on the different standards that would be relevant in different places. This raised significant debate. Some parts of the process do accept other standards e.g. IGARD.

### **Area Reports**

- 15 Updates from around the table.

### **Training Day**

- 16 It was noted that another Training Day should be planned. Target is June 2018.

### **Date of next meeting**

- 17 To be agreed for April if possible. Agenda will include plans for the Training Day.