

**57<sup>th</sup> Meeting of the Privacy Advisory Committee**  
**Wednesday, 21<sup>st</sup> January 2021 at 10:00am**  
**On-Line Web-Ex Meeting**

**Present:**

Privacy Advisory Committee: Prof Roy McClelland, Gillian Acheson, Brice Dickson, Brendan O'Neill, Colin Harper, Dr Clodagh Loughrey, Dr Michael McKenna, Geraldine Reynolds,

**In Attendance:**

Dr Michael Quinn, Head of Clinical Informatics, DHCNI Team/ Chair, HBS Governance Board  
Frances Burns, Project Manager, ADRCNI, Centre for Public Health, QUB

**1. Apologies**

Apologies were received from Prof Ian Young and Dawn Shaw.  
Prof McClelland advised that Dawn Shaw would be stepping down from her role as social care representative on PAC and he would follow up on a replacement representative.

**2. Honest Broker Service (HBS) / HDRUK BSO Secure e-Research Platform (UKSeRP)**

Prof McClelland welcomed to the meeting Dr Michael Quinn (Chair, HBS Governance Board/Head of Clinical Information, Digital Health & Care NI) and Dr Frances Burns (Project Manager, ADRCNI, QUB), who had been invited to provide an update on developments within the HBS and the HDRUK BSO Secure e-Research Platform (UKSeRP).

Prof McClelland advised that further to his previous discussions with Dr Quinn and Dr Burns, he felt it would be beneficial for PAC to receive an update on recent developments within the HBS, in terms of its ability to provide solutions to the research and clinical community in relation to data linkage etc. Discussion would also assist in informing how the new Advisory Body, to be established in line with the HSC (Control of Data Processing) Act 2016, will relate to the HBS in future, in respect of applications and processes.

**HDRUK BSO Secure e-Research Platform (UKSeRP)**

- The UKSeRP, which is part of the HDRUK infrastructure hosted by Swansea University, will enable researchers to remotely access and link data in a secure and governed environment, to which PAC had previously given its full support. Dr Frances Burns, (N. Ireland Project Lead) provided an update on progress;
- The UKSeRP software has been developed by the SAIL Databank (Secure Anonymised Information Linkage).

### **HDRUK National Core Studies Programme**

- Dr Quinn provided an overview of N. Ireland's participation in the HDRUK National Core Studies programme, which will enable the UK to use health data and research to inform responses to Covid-19. The programme comprises of six studies.
- N. Ireland's Chief Medical Officer and Chief Scientific Advisor had written to the Chief Executives of each of the HSC Trusts to request their support in N. Ireland's participation in these national studies.
- MOUs with the HSC Trusts and Department of Health (DoH) have been updated, sign-off from each of the Trusts is awaited.
- Significant progress has been made and the project is moving at pace.
- Funding has been allocated to support NI's involvement in the national core studies.
- A public engagement exercise will be undertaken. It was emphasised that this will be vital to ensure public support for the Programme.
- Work is ongoing in respect of the Covid-19 Vaccination Study – technical infrastructure has been created.

Dr Quinn advised that he is working with DoH colleagues in relation to the secondary use of information – it was noted that the current pandemic has highlighted the importance of sharing data for secondary purposes.

It is anticipated that the volume of requests to the HBS for access to data to facilitate research will increase significantly as the datasets are published and made available. Assurance was provided that adequate security mechanisms will be in place within the HBS. Datasets will be cohorted in an appropriate and anonymised form to ensure safety of data, allowing complete control over access. The Data Controller will have the ability to set caveats and restrictions on datasets.

Access to HSC data has assisted in informing the immediate response to the pandemic. The anonymisation of data is undertaken as far as possible - if access to patient identifiers is required, this will be undertaken within a secure and trusted research environment.

There was additional discussion regarding the future role of the HBS, beyond assisting in the response to the current pandemic eg: the use of pseudonymised data to enable data linkage, establishing of Registries etc.

Prof McClelland thanked Dr Quinn and Dr Burns for their informative update.

Dr Quinn advised that PAC would be kept updated on progress and confirmed that the HBS will seek assurance from colleagues within the Department of Health, PAC and the new Advisory Body, as and when required.

There was some discussion regarding the role of the new Advisory Body and its required skill-set. The requirement for the relevant technical expertise and an understanding of the processes in place within the HBS, was highlighted.

B O'Neill advised that it is expected that the role of the new Advisory Body will include oversight of the practices in place to anonymise data, to ensure that this is undertaken to an agreed standard.

**3. Minutes of the Previous Meeting ~ 24<sup>th</sup> June 2020**

The minutes of the previous meeting held on 24<sup>th</sup> June 2020 were agreed.

**4. Matters Arising:**

***i. NIECR Opt-Out***

Prof McClelland provided an update in relation to NIECR Opt-Out.

As previously advised, a small number of service users had requested to opt-out of the NIECR.

Prof McClelland and Gillian Acheson had been involved in a small working group, which had been established to inform the NIECR Steering Group on the withdrawal of the provision of opt-out. The working group had recommended that the wishes of the individuals who had requested opt-out should be respected, as they could see no ethical justification for over-riding their requests.

It was noted that the NIECR provides a single view of information throughout its interfaces to a wide range of clinical systems – if opted-out a patient's clinical information would not be available to Clinicians at the point-of-care, which may increase risk to patients.

It was also highlighted that NIECR is the only electronic source system used to record some patient information.

The Chair of the NIECR Steering Group had written to each individual who had expressed their wish to opt-out, to inform them of the implications of this decision on their care and the impact of Clinicians being unable to view their records.

It was noted that a number of those who had raised specific concerns and chosen to opt-out, had since reversed their decision and chosen to opt-in again.

B O'Neill advised that the Encompass Working Group is also considering the implications of service users wishing to opt-out. He noted that the Encompass system will provide a patient portal, providing service users with the ability to book appointments etc. This functionality may not be available to those who choose to opt-out.

PAC were asked to forward any additional comments on opt-out provision to Prof McClelland.

***ii. Joint Meeting with PDGs/IGAG ~ September 2020***

PAC had held an on-line meeting with Personal Data Guardians (PDGs) and Information Governance Advisory Group (IGAG) members on 16<sup>th</sup> September 2020, which had provided the opportunity to discuss experiences and issues arising from the current pandemic in relation to information privacy and patient confidentiality.

Dr Michael Quinn had joined the meeting to provide an update on the HSC Data Strategy and secondary uses.

**5. Chairman's Update**

***Conference Call with Dr Chris Bunch and Sandra Lomax, Caldicott Council***

Prof McClelland provided an update on his recent discussions with Dr Chris Bunch and Sandra Lomax from the Caldicott Council, in relation to links between the Caldicott Guardians and the NI PDGs and how the Council could support PDGs in undertaking their role. Dr Paddy Woods, Deputy CMO, had previously represented the NI PDGs on the Caldicott Council.

Dr Bunch had noted that the role of Caldicott Guardian had, in some cases, been allocated to the Director of Nursing. Prof McClelland sought PAC's views on whether this could be considered for NI PDGs, given the increasing and competing demands on Medical Directors and their ability to allocate time to the role of PDG. Discussion followed.

Dr McKenna highlighted the need to promote the role within primary care, which is currently undertaken within each individual practice. The appointment of a number of Data Champions within primary care, to assist colleagues at practice level, had been considered, although not yet progressed.

The need for PDGs to have specialist knowledge of data protection, GDPR legislation etc was also emphasised.

It was suggested that the role could be assigned to a team within each Trust, as opposed to an individual.

The possibility of assigning the role to a Director of Nursing or a Deputy Medical Director was also discussed.

The need for data champions within the charity sector was also highlighted.

It was agreed that it would be beneficial to obtain the views of the current PDGs, which could possibly be an item for discussion at the next joint meeting in September 2021. Prof McClelland noted that he had discussed this issue with Dr Naresh Chada, Deputy CMO, who may discuss with Medical Directors in the interim via the Medical Leaders Forum, however it was acknowledged that this forum does not include the Executive Directors of Social Care.

Brendan O'Neill advised that colleagues at the Department of Health were considering the possibility of appointing a Departmental Medical Officer, with responsibility for creating a regional forum for PDGs.

**6. HSC (Control of Data Processing) Act 2016 - Update Brendan O'Neill**

Brendan O'Neill advised that work is progressing as far as possible in relation to the drafting of Regulations associated with the HSC (Control of Data Processing) Act 2016. The response to the pandemic has impacted on progress.

The specific requirements of the new Advisory Body to be established are also being considered. B O'Neill will keep PAC updated of progress.

**7. Information Governance Update – Brendan O'Neill**

Extension of Data Adequacy Arrangements

Brendan O'Neill advised that an agreement is in place between the UK government and EU authorities to extend Data Adequacy arrangements for a 6 month period, which includes provision for the continued flow of personal data between the EU and the UK, while work on data adequacy decisions is completed.

Covid-19

Work is ongoing in relation to the response to Covid-19.

MOUs are in place in relation to sharing of N. Ireland data.

DPIAs and Privacy Notices have been reviewed.

Work is also ongoing in relation to the analysis of all data which has been accumulated to date in relation to the pandemic, including ownership of data and governance arrangements in respect of any future use.

Vaccine Management System

Gillian Acheson advised that Trust IG Leads had recently been involved in discussions with DOH colleagues in relation to the Vaccine Management System; including DPIAs, DAAs and Privacy Notices. A number of data control issues had been identified and work was ongoing to address these.

**8. Any Other Business**

**PAC Review of Progress 2020**

Prof McClelland referred to the circulated PAC Review of Progress report for 2020, which he would forward to Brendan O'Neill, for onward distribution as appropriate.

**Action: Prof McClelland/Brendan O'Neill**

## **9. Dates for 2021 Meetings of PAC**

The 2021 meetings of PAC had been scheduled for the following dates:

- Thursday, 15<sup>th</sup> April 2021 @ 10:00am
- Thursday, 24<sup>th</sup> June 2021 @ 10:00am
- Thursday, 16<sup>th</sup> September 2021 @ 10:00am (joint meeting with PDGs/IGAG members).
- Thursday, 18<sup>th</sup> November 2021 @ 10:00am