

**56<sup>th</sup> Meeting of the Privacy Advisory Committee**  
**Wednesday, 24<sup>th</sup> June 2020 at 10:00am**  
**On-Line Web-Ex Meeting**

**In Attendance:**

Privacy Advisory Committee: Prof Roy McClelland, Prof Ian Young, Brice Dickson, Brendan O’Neill, Colin Harper, Geraldine Reynolds, Gillian Acheson

Queen’s University, Belfast: Prof Stuart Elborn, Prof Mark Lawler, Prof Judy Bradley, Bernadette Boyle

**1. Apologies**

Apologies were received from Dr Clodagh Loughrey, Dr Michael McKenna and Dawn Shaw.

**2. Belfast Region City Deal: NEW Institute for Research Excellence in Advanced Clinical Healthcare (i-REACH) facility - Prof Stuart Elborn, Queens University Belfast**

Prof McClelland welcomed Prof Stuart Elborn and colleagues from QUB to the meeting to discuss the new i-REACH facility.

An overview was provided of the Belfast Region City Deal and Global Innovation Institute (GII) and the Institute for Research Excellence in Advance Clinical Healthcare (i-REACH). Presentation as circulated. Discussion followed:

- It was noted that discussion has taken place with the Department of Health in relation to the i-REACH facility, including links with the Encompass Programme;
- The importance of ongoing citizen engagement was highlighted – the public will be involved in the development of infrastructure, to optimise engagement with research, working together to engage and involve diverse voices to help create a collective, coherent approach, that affirms the importance and value of patient and public views on data uses. Patient and client groups will be consulted throughout the process;
- Fair Value Principle was highlighted – it was agreed that benefits from research must flow back to patients;
- PAC stressed the importance of transparency and clarity in the process to ensure that the views of the public are sought on the sharing of data;
- The importance of obtaining consent for patient participation in clinical trials was also discussed ~ discussions have taken place with the Encompass Programme in this regard. Citizen engagement will take place to obtain feedback on the views and values of NI society, which it was acknowledged, may differ to those held in other areas;
- PAC also emphasised the importance of having a secure, trusted research environment in place ~ similar to the existing arrangements in place within the NI Honest Broker Service (HBS);
- It was noted that the wishes of those who wish to opt-out of data sharing should be respected and mechanisms should be in place to facilitate this;

- It was acknowledged that the current pandemic has emphasised the importance of having access to accurate, real-time health data to facilitate the re-purposing of services and enhancement of future service provision;
- It was suggested that a multi-disciplinary scoping exercise be undertaken to engage further with a range of stakeholders.

Prof McClelland thanked Prof Elborn and colleagues for their update on developments in relation to the i-REACH facility. Prof Elborn agreed to keep PAC updated on progress, with further consultation going forward.

Prof McClelland informed PAC that he had invited Dan West, Chief Digital Information Officer, to attend the joint meeting of PAC with Personal Data Guardians (PDGs) and possibly Information Governance representatives, scheduled for 16<sup>th</sup> September 20, which should provide the opportunity for the Department to provide an update on progress in relation to the i REACH facility.

### **3. Minutes of the Previous Meeting ~ 14<sup>th</sup> November 2019**

The minutes of the previous meeting held on 14<sup>th</sup> November 2019 were agreed.

### **4. Matters Arising:**

#### ***i. National Breast & Cosmetic Implant Registry***

Prof McClelland advised that the views of PAC in relation to the above Registry had been acknowledged by the Department of Health and NI data will be included in the national Registry going forward, based on patient consent.

#### ***ii. CAG Non-research Application (Enc 1)***

As previously discussed, it is expected that many of the research applications received by the new NI Advisory Body will previously have been considered by the Confidentiality Advisory Group (CAG). The merit in standardising the research application documentation had been discussed and agreed with CAG.

It was agreed that the existing CAG non-research application form could be adapted for use in relation to access to NI data and this can be progressed once the Regulations associated with the new legislation are made available.

Prof McClelland advised that he had access to previous 'Guidance Notes' for use with the non-research application form, which could also be updated for use with applications for NI data.

Prof Young, confirmed that there is a mechanism in place to update the existing Integrated Research Application System (IRAS) application forms, to facilitate the inclusion of NI data.

### **5. Chairman's Update**

#### ***COVID-19 Requests***

Prof McClelland provided an update in relation to the number of requests for advice

which had been received by PAC since March 2020, all of which had been in relation to Covid-19 - the majority of which were in relation to inclusion of NI data in national studies.

PAC had also responded to a request for advice from the Department of Health regarding processing of data in relation to the current pandemic.

Advice had also been sought from a number of the NI Information Governance Leads, again in relation to Covid-19.

### ***2020 Personal Data Guardian Training***

Prof McClelland advised that he had arranged to speak with Diane Taylor, Head of the HSC Leadership Centre, that afternoon to discuss progression of the arrangements for the 2020 PDG training and would provide PAC with an update on the outcome of discussions. It is hoped that the 2020 training can be delivered virtually.

## **6. NIECR Opt-out**

Prof McClelland referred to previous discussion in relation to NIECR Opt-Out and the two enclosures which had been circulated: a summary of the specific objections which had been received by the NIECR Steering Group from service users, along with an overview of the impact of opt-out on delivery of care by clinicians.

- 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 the clinician at the point-of-care, which may increase risk to patients eg: possible delays to treatment.
- It was also highlighted that NIECR is the only electronic source system used to record some patient information eg: current diabetes and asthma pathways. If a patient opts out, their information may not be available electronically at the point of care.
- Prof McClelland advised that following the initial PAC communication on the issue, he had discussed the matter further with the ICO and had also requested guidance from the GMC, with a response awaited.
- Discussion followed on patient requests for their information to be deleted and the resulting impact of this on healthcare professionals and delivery of care.
- It was noted that the deletion of clinical records would impact on the ability of a healthcare professional to justify the care provided, in the event of a subsequent complaint/legal action.
- It was also noted that opt-out and the inability for a clinician to access electronic records may impact on patient care and service delivery – longer consultation times will impact on other service users.

- The legal implications of opt-out/deletion of data were also discussed – including GDPR legislation.
- The retention policies for data which are in place within HSC Trusts were also highlighted eg: Good Management Good Records, which set specific timeframes for the retention of data, which are necessary for litigation purposes.
- It was also noted that data retention policies are in place in relation to participation in clinical trials.
- The impact of opt-out on the ability to provide emergency medical care was also noted.
- Clarification is required on the process for the ‘unlocking’ of patient records in the event of a patient wishing to opt-in again ie: how is this undertaken, the time-frame required and allocation of responsibility for this.
- The importance of patients being made fully aware of the implications of ‘opt-out’ was emphasised.

It was agreed that it would be of benefit to receive clarification on the issue from the GMC, Prof McClelland to follow up on response and will update PAC on progress.

## **7. Joint meeting with PDGs and IGAG**

Prof McClelland advised that he had sought the views of PDGs in relation to holding an on-line joint meeting with PAC in September 20, given the current restrictions. Those who had responded to date had been in favour of holding an on-line meeting, as it would provide the opportunity to discuss the experiences and issues arising from the current pandemic in relation to information privacy and patient confidentiality.

Prof McClelland advised that he had invited Dan West, Chief Digital Information Officer, to attend the meeting to provide an update on the Data Strategy and secondary uses.

It was agreed that as in previous years, the meeting invitation should also be extended to members of the Information Governance Advisory Group (IGAG). PDGs and IGAG members would be asked to forward any specific issues for discussion in advance of the meeting. Platform for the meeting and further details to be confirmed.

## **8. 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 and will keep PAC informed of developments.

**9. Information Governance Update – Brendan O’Neill**

B O’Neill advised that work is ongoing to streamline the process in relation to the inclusion of NI data within national audits. A check-list will be made available for completion by those responsible for contributing to national audits, which will direct applicants to PAC if data is not in an anonymised form.

Gillian Acheson noted that IG Leads were receiving an increasing volume of requests for the inclusion of NI data within national audits and the agreed process will assist IG staff in ensuring appropriate governance arrangements are in place.

**10. Any Other Business**

No further items for discussion.

**11. Dates for 2020 Meetings of PAC**

- Wednesday, 16<sup>th</sup> September 2020 (Joint Meeting of PAC with PDGs and IGAG)
- Thursday, 19th November 2020