

**58<sup>th</sup> Meeting of the Privacy Advisory Committee**  
**Thursday, 24th June 2021 at 10:00am**  
**On-Line Web-Ex Meeting**

## **MINUTES**

**In Attendance:**

Prof Roy McClelland (Chair), Brendan O'Neill, Brice Dickson, Colin Harper,  
Dr Michael McKenna, Gillian Acheson, Geraldine Reynolds

**1. Apologies and Welcome**

Apologies were received from Dr Clodagh Loughrey.

**2. Minutes of the Previous Meeting**

The minutes of the previous meeting held on 21<sup>st</sup> January 2021 were agreed.

**3. Matters Arising**

**Role of Personal Data Guardian**

Prof McClelland referred to previous discussion regarding the role of the PDG at the January 21 PAC meeting.

He advised that subsequent to this, he had contacted Dr Naresh Chada, Deputy CMO, who had not yet had the opportunity to discuss the role of PDG with Medical Directors, due to current pressures within the HSC. He had endorsed raising the issue for discussion at a future meeting of PDGs with the Privacy Advisory Committee (PAC), in order to obtain their views.

Brendan O'Neill advised that colleagues at the Department of Health (DOH) were considering the possibility of appointing a Departmental Medical Officer who would have responsibility for creating a regional forum for PDGs, however there had been no further progress on this appointment as yet.

Following discussion, PAC agreed that the role of PDG should be discussed at their joint meeting with PAC in September 21. It was therefore agreed that the joint meeting this year should be confined to PAC/PDGs - IGAG representatives would not be invited to join the meeting.

Prof McClelland agreed to write to IGAG members to advise that the September 21 joint meeting would be restricted to PAC/PDGs only – he would offer to meet with IGAG at a separate forum. Gillian Acheson advised that she would also update IGAG members on this decision at the forthcoming Information Governance Network meeting in August 21.

**Action: RMCC / GA**

**4. Chairman's Update**

**PAC Activity**

Prof McClelland provided an update on PAC activity and requests for advice in recent months - predominantly queries in relation to Covid-19, particularly in relation to N. Ireland's participation in a number of national studies including, vaccine development and efficacy, antibody development, monitoring etc.

Discussion followed in relation to some ongoing issues with N. Ireland's participation in National Audits, including:

***The National Haemophilia Database:***

- Prof McClelland advised on the need to ensure that a formal mechanism is in place for the contribution of N. Ireland patient data to the above database - the current arrangement is largely linked to direct care and clinical audit however, a formal process for obtaining patient consent will be implemented, in the absence of Section 251 provision in NI.
- Prof McClelland had discussed the issue with the Clinicians involved and it had been agreed that all future engagement with the National Database would be on a consenting-in basis and arrangements will be put in place to facilitate this. Formal consent will be sought from all patients at their next engagement with the Clinicians. Prof McClelland advised that he was content with the outcome of these discussions and the agreed process going forward.
- It was noted that any requests for patient data to be removed from the existing national database will be facilitated.

Brendan O'Neill highlighted the importance of ensuring that adequate governance arrangements and documentation are in place in relation to NI's participation in such national studies, including DPIAs.

He provided an update on the implementation of the **Medical Devices Act, 2021**, which is in the process of being passed by Parliament.

- Information recorded on this national database will include patient identifiers, as well as details on where procedures have been performed, device used etc. Research will be undertaken to identify any issues/areas of concern eg: problems with specific implants, need for recall etc;
  - Legislation for the creation of the Medical Devices database is UK-wide. NHS Digital will collect and process data and any issues identified will be raised with the other UK nations, who will review their dataset and determine if action is required;
  - Consent will be obtained from patients prior to entry of their details onto the national database;
  - Brendan O'Neill agreed to seek clarification on whether the database will include retrospective data, for those patients who have already had a medical device implant;
- Action: BO'N**
- He advised that the DOH would lead on this piece of work within NI and would issue any communication in respect of this on behalf of all HSC organisations.

***NICOR (National Institute for Cardiovascular Outcomes Research);***

- Prof McClelland and Gillian Acheson provided an update on the ongoing discussions with NICOR in relation to NI's participation in these national audits, the requirement for Data Access Agreements (DAAs) as required; as well as the pivotal role of the NI Honest Broker Service (HBS) in facilitating NI's participation. Transfer of NI data is officially on hold. Discussions are ongoing.

## **National Audit of Pulmonary Hypertension (NAPH)**

- Gillian Acheson provided an overview in relation to the National Audit of Pulmonary Hypertension. NHS Digital are collecting the relevant data and as they are set up under legislation, they require a direction from the NI Chief Medical Officer, to instruct them to collect the relevant information. However, the relevant legislation is not applicable within NI.
- The HSCB are currently in discussions with NHS Digital with regards to the development of a Section 255 letter and it is hoped that the issue will be resolved soon. Outcome awaited. It was noted that patient consent is required for participation in this national study.

It was emphasised that the use of the NI HBS will reduce the requirement for DPIAs and will facilitate NI's participation in national audits.

## **Use of Primary Care Data for Secondary Uses**

Discussion followed regarding the impact on the N. Ireland population, in relation to concerns around the gathering of patient data held by GP practices in England by NHS Digital, to feed into a central NHS database for planning and research purposes.

Dr McKenna and G Acheson noted that there had been a significant rise in the number of requests to opt-out from NI patients following recent media coverage.

It was noted that the roll-out of the scheme in England had been delayed until September, to allow patients more time to opt out, to avoid their information being shared from their GP records.

Brendan O'Neill advised that the DOH had issued a statement to clarify that the scheme for the use of primary care data in England did not apply to N. Ireland and therefore patients did not require to opt-out.

The benefits of access to primary care data and its appropriate use were acknowledged. However, it was emphasised that public engagement and transparency in the process were essential to avoid loss of public confidence in how patient data is stored and accessed.

The value of being able to collect information at a national level to provide vital data for research and development of new treatments was noted, particularly so with the impact of the current pandemic.

Discussion followed regarding the impact of Covid-19 on public perception of the importance and value of sharing information and the use of data with minimum identifiers to enable life-saving processes, including fast track research on efficacy of vaccines etc.

However, it was also noted that tight controls will be required on the subsequent use of any data which has been collected to facilitate the response to the pandemic. Consent and/or anonymisation of data should still be considered.

## 5. Joint Meeting ~ 16<sup>th</sup> September 2021

The agenda for the forthcoming joint meeting of PAC with Personal Data Guardians (PDGs) in September 21 was discussed:

- **PAC Activity** ~ Prof McClelland will provide an overview of recent PAC activity and requests for advice;
- **Role of the PDG** ~ it was agreed that the focus of the meeting should be on the role of the PDG. Prof McClelland proposed inviting Dr Chris Bunch, Chair of the UK Caldicott Guardian Council, to join the meeting to share his expertise on the role of the Caldicott Guardians in England. PAC agreed with this proposal, Prof McClelland will follow up on this invitation;

**Action: RMcC**

- **Cyber-security and IG implications for PDGs** ~ it was agreed that the importance of the PDG role in light of recent cyber-security (including the HSE and QUB) and the resulting impact on patient services should be raised; there is a need to ensure that PDGs are fully aware of the impact of their decision-making in relation to protecting patient data and impact of recent data breaches. Brendan O'Neill agreed to lead on this discussion;
- It was agreed that a briefing session should be provided to PDGs to ensure they are aware of the impact of their role on data security and have an adequate appreciation of the risks involved for the HSC organisations in the sharing of data, with a focus at strategic level as opposed to the technical detail;
- It was acknowledged that although PAC's primary role is in relation to patient confidentiality, there is an interface between maintaining confidentiality and cyber-security; HSC organisations need to have confidence in the external organisations that data is shared with;
- It was highlighted that any requests to the new Committee, to be established under the new legislation in N. Ireland, will need to include information on security arrangements and safeguards in place to ensure that data will be held in an appropriate manner – recent events have highlighted the increasing requirement to focus on cyber-security and data protection going forward.

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

Brendan O'Neill provided an update on progress regarding the implementation of the above legislation;

Progress has been impacted by the ongoing response to the pandemic;

Prof McClelland raised concern regarding the delay on the implementation of the legislation and associated Regulations, given that the above Act had been passed 5 years ago - he asked B O'Neill to convey this to Dan West, Chief Digital Information Officer, on behalf of PAC;

Prof McClelland highlighted the importance of ensuring that Registries such as the NI Cancer Registry were on a statutory footing;

Brendan O'Neill advised that discussions are ongoing in relation to planning for the public consultation exercise, prior to the implementation of Regulations, which will take a minimum of 6 months.

B O'Neill provided an update on the Covid-19 Vaccination Certificate Scheme; discussion had taken place with relevant stakeholders and this will help inform how HSC information is used for direct and secondary uses;

Dr McKenna noted the requirement for patients to be able to access their own data and the need for further discussion on this issue, including what information should be readily available and what aspects will require consultation with Clinicians; *eg*: proof of vaccination *etc*.

## **7. Information Governance Update: Brendan O'Neill**

Brendan O'Neill provided an update in relation to Information Governance:

The majority of discussion and ongoing work has been in response to the recent cyber-security incidents and data breaches; there is an increased awareness of the need to ensure that partnerships and data sharing agreements with third parties are strengthened. A Task & Finish Group had been established involving SIROs to identify and audit existing data flows. Work is ongoing.

Gillian Acheson noted that Information Governance Leads are currently reviewing the selection criteria for data sharing contracts, which have become more stringent at the contract framework stage; recent data breaches have emphasised the need to ensure adequate data protection with improved cyber-security and associated infrastructure to support this.

SIROs are also ensuring that Risk Registers within the HSC are being discussed and raised at Executive/Board level, in relation to information governance.

Gillian Acheson provided an update on ongoing work regarding the Victims' Payments Scheme and Personal Independence Payment (PIP) Scheme in NI and the associated information governance requirements.

## **8. Any Other Business**

No further business.

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

- Thursday, 16<sup>th</sup> September 2021 at 10:00am (Joint Meeting with PDGs/IGAG);
- Thursday, 18<sup>th</sup> November 2021 at 10:00am.