

## 55<sup>th</sup> Meeting of the Privacy Advisory Committee

Wednesday, 14<sup>th</sup> November 2019 at 10:00am

Venue: Meeting Room 1, A-Floor, Belfast City Hospital

**Present:** Prof Roy McClelland (Chair), Dr Colin Harper, Gillian Acheson, Brendan O'Neill, Dawn Shaw, Dr Clodagh Loughrey, Dr Michael McKenna, Prof Ian Young

### 1. Apologies

Apologies were received from Prof Brice Dickson and Geraldine Reynolds.

Prof McClelland welcomed Dawn Shaw, Deputy Executive Director of Social Work and Children's Community Services, Belfast HSC Trust, to the Committee. Dawn had replaced John Growcott as representative from social care.

### 2. Encompass Information Governance Team

Prof McClelland welcomed Claire Staple, Solicitor Consultant and Ella Jameson, Senior Project Manager, Encompass, to the meeting.

Claire and Ella provided an overview on progress in relation to Encompass, the HSC wide initiative to provide an integrated digital care record for N. Ireland:

- It was noted that the Encompass system will include a patient portal, enabling service users to access their own information, communicate with their health and social care team, view tests results and manage appointments etc. There are a number of issues in relation to the patient portal to work through, including identity assurance, proxy access and deteriorating / increasing capacity.
- It is planned that the go-live on the initial HSC site will take place in October 2021;
- The Encompass structure and governance arrangements were outlined, including the Regional Programme Board and Team, which will include representation from all HSC Trusts, HSCB, BSO and DOH;
- IG Workstream – work is underway to identify the Chair and membership of this multi-disciplinary group. Prof Ian Young requested that representation from the N. Ireland research community be included on this Group;
- DPIA – as required by GDPR legislation, preliminary work has commenced and is at an early stage; initial discussions have been held with BSO and ICO; the design and configuration of the DPIA will be under continuous review and it is anticipated that NI Personal Data Guardians will be involved in discussions;

- The Encompass Data Sharing Agreement was outlined, which will include a role based access and consent model, subject access request model and provision for security/audit arrangements;
- A full programme of engagement with the public will take place, it was noted that service users had been involved in the initial stages of the project, including the evaluation of demonstrations;
- There was some discussion regarding the future role of the NI Honest Broker Service (HBS) in the provision of access to anonymised data for research purposes and whether its current functionality would be maintained, following the implementation of the Encompass system;
- Opt-in and Opt-out - functionality will be provided to allow patients to 'opt-in' and consent to the use of their identifiable data for research purposes. It was noted that other sites have maximised this 'opt-in' functionality, enabling patients to consent to their identifiable data being used for specific research projects/clinical trial purposes;
- It was noted that it will not be possible for patients to 'opt-out' of their data being included on the Encompass system (as is currently the case with NIECR). The need for a full public engagement programme, to outline why this is not possible, was highlighted;
- It was noted that due to data quality issues, Encompass will not provide access to full historical data, which can be accessed via the NIECR;
- The Encompass system will enable intra-operability with existing GP systems, as is the case for NIECR – facilitating the creation and tracking of electronic referrals;
- There was some discussion regarding the complex issues in relation to the inclusion of social care data within Encompass;

Prof McClelland thanked Claire and Ella for their update on progress and asked that PAC be kept up to date and informed in relation to future developments, particularly in relation to confidentiality issues.

Dr McKenna advised that he is a member of the Encompass Program Board and the NIECR Governance Group and will be in a position to keep PAC updated.

### **3. Minutes of the Previous Meeting**

The minutes of the previous meeting held on 10<sup>th</sup> Aril 2019 were agreed.

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

#### **i. Joint meeting with PDGs and IGAG ~ 18<sup>th</sup> September 2019**

Prof McClelland referred to the joint meeting of PAC with Personal Data Guardians

(PDGs) and Information Governance Advisory Group (IGAG) in September 2019. Dr Tony Calland, Chair, and Natasha Dunkley, Head of Admin, Confidentiality Advisory Group (CAG), had been invited to attend the meeting, to discuss the role and function of CAG, which will be of benefit to PAC and the new Advisory Body to be established under the new HSC Control of Data Processing legislation.

The initial discussions held at the joint meeting will assist in establishing formal communication channels with CAG going forward.

It is expected that many of the research applications received by the new Advisory Body in N. Ireland will previously have been considered by CAG.

The need to standardise research application documentation had been noted during the discussions with CAG.

Natasha Dunkley had advised on the ongoing work to review and update the documentation within the Integrated Research Application System (IRAS).

There was some further discussion in relation to the role of the N. Ireland HBS. PAC were in agreement that the role of the HBS, in the provision of access to anonymised data, is undertaken in a secure environment in both an ethically and legally sound manner and is a legitimate use of data for HSC purposes. It was noted that to date, the anonymised data has only been accessed by the N. Ireland HSC organisations.

There was some discussion regarding the remit for the use of personal data for '*direct care*' purposes ie: ensuring that the care delivered to patients is 'best practice'. It was agreed that the provision of access to anonymised HSC data by the HBS, provides a valuable means to ensure that this 'best practice' is maintained in the delivery of care to patients. Access to data in an anonymised form allows for benchmarking of data.

It was highlighted that the implementation of the new legislation in N. Ireland, will provide certainty and clarity on the matter and ensure that the HBS is operating on a lawful basis.

Prof McClelland referred to the discussion which had taken place at the joint meeting in September regarding the onus on HSC organisations to ensure that GDPR requirements are met in the processing of personal data, as well as the obligation to adhere to the common law duty of confidentiality - ie: it had been queried if there were instances when GDPR requirements had been adhered to, however the common law duty of confidentiality had not been met? There was some further discussion on this issue.

It was highlighted that although adherence to GDPR requirements is a necessity, it may not be sufficient in relation to data processing. HSC organisations also need to consider whether the common law duty of confidentiality has been met.

## **ii. NHS Blood and Transplant (NHSBT) Application**

Prof McClelland referred to discussion which had taken place at the previous PAC meeting in April 2019, which Dr Dominic Trainor (Regional Lead for Organ Donation in N. Ireland & Clinical Lead for Organ Donation, Belfast HSC Trust), had attended, to discuss the ongoing work of NHSBT in relation to organ donation and the collection

of potential donor audit information within N. Ireland.

Dr Trainor had provided further clarification on the work of the Specialist Nurses for Organ Donation (SNODs) within the clinical team; and also the physiological status of patients being considered for inclusion in the Potential Donor Audit (PDA)/Referral database, whose records would be the subject of review and data extraction by the Specialist Nurses.

Subsequent to this discussion, Prof McClelland had written to Alison Gane, Information Systems Security Manager, NHSBT, to outline the views of PAC in relation to the PDA/Referral Data collection (copy of letter of 25<sup>th</sup> April 2019 was circulated for reference). He had advised that in view of the current absence of legislative regulations in N. Ireland, while there is strong public interest in confidentiality, consent is not an option and a balancing may be required with the competing public interests in disclosure to the NHSBT. PAC had considered the accessing of patient records, in these specific circumstances, to be justified in the public interest.

However, PAC are also of the opinion that all hospital in-patients should be informed of such potential disclosures and their wishes should normally be respected. It was proposed that this information could be included with the information given to patients on the data sharing which is necessary for their care and for assuring and improving the quality and safety of patient care generally.

PAC had advised that the NHSBT data sharing arrangements should, as soon as reasonably practical, be brought within the remit of the HSC (Control of Data Processing) Act 2016.

A copy of the response to PAC from Alison Gane (28<sup>th</sup> August 2019) was circulated for reference.

### **iii) NISRA's Administrative Data Research (ADR-NI) and Health Projects**

Prof McClelland referred to the circulated, recent correspondence between himself and Orla Bateson, NISRA's Administrative Data Research Centre (ADR-NI), October 2019, regarding the use of secondary health data for research purposes.

ADR-NI had sought the views of PAC regarding their most recent proposals in relation to the use of secondary health data for research purposes for health related research within the ADR-NI, via the use of the Northern Ireland Longitudinal Study (NILS), which allows for secondary healthcare data to be linked on a project by project basis.

Further to review, PAC had considered the proposals built around the NILS database, to be comprehensive and clear and, as with previous NILS linkage initiatives, from a patient confidentiality perspective, PAC consider the arrangements exemplary for health research.

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

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

Prof McClelland referred to the recent correspondence with the Department of Health (DOH) regarding the inclusion of N. Ireland patients in the national Breast & Cosmetic Implant Registry (BCIR). The primary purpose of the Registry is as a direct care patient record, to provide an accessible system for the traceability of patients in the event of a product safety issue and recall. A secondary purpose is that it also enables the identification of possible trends and complications relating to specific implants. The DOH had sought the views of PAC on the proposal to include N. Ireland data within this national database.

PAC had considered the proposals and responded to DOH, copy of response letter, 22nd October 2019, was circulated for reference.

It had been agreed that the proposed data sharing is part of a patient's 'direct care'. However, the assumption of patient implied consent for such sharing is probably unjustified, given that their data will be flowing outside of N. Ireland. It had been agreed that it would be preferable to seek 'express consent' for any proposed disclosure to NHS Digital.

The alternative approach of retaining all patient identifiers within NI, via the use of the HBS, had also been noted.

Prof McClelland referred to the subsequent communication issued by the Chief Medical Officer to HSC Trusts, 4th November 2019, copy as circulated. It was noted that engagement with HSC staff is ongoing in relation to access to the national registry and the associated working procedures, including the relevant consent issues.

PAC agreed that patients undergoing such procedures will need to be clearly informed of exactly how their data will be used and shared and the purpose for this.

It was noted that retrospective data will not be included on the Registry.

Brendan O'Neill agreed to keep PAC informed on further developments.

## **6. Advisory Committee for New HSC Act**

Prof McClelland advised that PAC will act as a shadow committee to the new Advisory Committee, which is to be established under the HSC (Control of Data Processing) Act 2016, pending a public appointment process. This arrangement will help to ensure continuity of provision and experience during the transition to the establishment of the new Committee.

Further to discussion at the previous meeting, Prof McClelland had sought expressions of interest from existing members of PAC in undertaking the role of deputy Chair for PAC. Colin Harper had agreed to undertake this role.

Discussion had been held with Dr Tony Calland, Chair of the Confidentiality Advisory Group (CAG), and Natasha Dunkley, Head of Confidentiality Advice Service, at the joint

meeting with PDGs/IGAG in September 19, regarding the activities and processes of CAG.

Brendan O'Neill advised that representatives from DOH had also met separately with Dr Calland and Ms Dunkley to discuss the proposed role and function of the new N. Ireland Committee to be established under the new legislation.

It is expected that many of the research applications received by the new Advisory Body will previously have been considered by CAG. As had been discussed with CAG, the merit in standardising research application documentation had been highlighted.

Natasha Dunkley had advised on the ongoing work regarding the review of the existing Integrated Research Application System (IRAS) application forms.

It was agreed that the IRAS forms could be reviewed and updated in line with research requirements for inclusion of N. Ireland data (noted that IRAS documentation relates to access to data for research purposes only).

It was highlighted that CAG is an advisory body and the new N. Ireland Committee will be required to make legislative decisions in relation to access to data.

It was agreed that it would be mutually beneficial for PAC to communicate with CAG in relation to the review of the application documentation, to aim to achieve a consistent approach. Separate questions could be included in the application process for those wishing to access N. Ireland data.

It was noted that 'opt-out' functionality will be required of the new Committee, to respect the wishes of service users who do not wish their data to be made available for research purposes.

PAC will continue to support the use of the N. Ireland HBS for access to anonymised HSC data for research purposes.

Prof McClelland agreed to contact CAG to request a copy of their application form for non-research requests.

**Action: Prof McClelland**

Prof Ian Young agreed to obtain further detail regarding the content of the IRAS application forms.

**Action: Prof Ian Young**

## **7. HSC (Control of Data Processing) Act 2016**

Brendan O'Neill provided an update on the above legislation. Work is progressing as far as possible, pending Ministerial appointment.

Work is ongoing on the draft Terms of Reference for the new Advisory Committee.

Work is also progressing in relation to the impact of GDPR/DPA18 on the new legislation, including consideration of 'opt-out' provision.

It is hoped that draft regulations for the new legislation will be available soon, on which the views of PAC will be sought.

**8. Information Governance Update**

No further update.

**9. Any Other Business**

None.

**10. Dates for 2020 PAC Meetings**

- Thursday, 23rd January 2020
- Wednesday, 8th April 2020
- Thursday, 25th June 2020
- Wednesday, 16<sup>th</sup> September 2020
- Thursday, 19th November 2020