

52nd Meeting of the Privacy Advisory Committee

Wednesday, 12th April 2018 at 10:00am

Venue: Room 22, 9th Floor, Main Site Tower, Queens University Belfast

Present: Prof Roy McClelland (Chair), Prof Brice Dickson, Dr Colin Harper, Gillian Acheson

In attendance: La'Verne Montgomery – Director of Corporate Management, Department of Health
Sharon Anderson - Information Management Branch, Department of Health

1. **Apologies and Welcome**

Apologies were received from Dr Clodagh Loughrey, Dr Michael McKenna and Geraldine Reynolds.

Prof McClelland welcomed La'Verne Montgomery and Sharon Anderson from the Department of Health. L Montgomery provided an overview of her role as Director of Corporate Management, including overseeing secondary uses legislation and ongoing preparation for GDPR implementation.

Prof McClelland advised that he would follow up with John Growcott to seek a replacement representative on the Committee from within social care.

Prof McClelland

2. **Minutes of the Previous Meeting ~ 24th January 2018**

The minutes of the 51st meeting of the PAC held on 24th January 2018 were agreed.

3. **Matters Arising:**

i. **Patient Participation in Research**

Prof McClelland referred to the PAC's Advice Note '*Patient Participation in Research in Primary Care (March 2017)*' which provides guidance in relation to the role of Research Nurses within the primary care setting. This Advice Note had been forwarded to Dr Margaret O'Brien, Assistant Director of Integrated Care at the Health & Social Care Board, in January 2018, for circulation within primary care.

Following discussion with Personal Data Guardians (PDGs) at the September 2017 joint meeting, PAC had adapted this Advice Note to apply to Trusts and all other HSC bodies. Prof McClelland confirmed that this Advice Note had been circulated to PDGs, as well as to members of the Information Governance Advisory Group, for onward distribution.

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

Prof McClelland advised that he was still in discussions with Dr Paddy Woods, PDG/Deputy CMO, regarding the work of NHSBT staff, who are involved in the collection of potential donor audit information within N. Ireland. PAC had previously raised concern in relation to data extraction being undertaken by NHSBT staff, who are not employees of the HSC in N. Ireland, and who do not have a direct care relationship with potential donors.

Dr Woods had raised the issue at a recent meeting of the N. Ireland Medical Leaders Forum, to consider how the issue could be addressed, to ensure practice is consistent with the Code of

Practice on Protecting the Confidentiality of Service User Information (COP) ie: data access/extraction should be undertaken by a member of staff who has a direct care relationship and/or consent should be obtained.

Dr Woods had advised that the issue will again be discussed at a subsequent meeting of this Forum and had agreed to update Prof McClelland on progress.

The importance of optimising processes to facilitate organ donation were recognised. La'Verne Montgomery agreed to discuss with Departmental colleagues to see if any further steps could be taken to progress the issue. Item to remain on this agenda. Prof McClelland will continue to liaise with Dr P Woods on the matter.

Prof McClelland / La'Verne Montgomery

4. Chairman's Update

i. Intensive Care National Audit & Research Centre (ICNARC) Data Flows

Prof McClelland advised that he and Dr Paddy Woods, were continuing discussion with ICNARC, in relation to N. Ireland's participation in two national clinical audits – National Cardiac Arrest Audit and Case Mix Programme.

While the value of N. Ireland's continued participation in these national audits was recognised, it was agreed that there is a need to ensure the secure transmission of data and to minimise the transfer of patient identifiers outside of N. Ireland. Discussions are ongoing regarding the options available to achieve this - including the potential adjustment of data requirements and pseudonymisation of data.

Dr Woods had discussed the matter at a recent meeting of the N. Ireland Medical Leaders Forum.

ICNARC have advised that a workaround solution had been identified to facilitate N. Ireland's continued participation in these national audits, however this will require an upgrade to IT systems and a change in existing processes. Prof McClelland had requested further clarification from ICNARC on the proposed solution, in particular confirmation on what individual patient information will be used and the anticipated time-frame for implementation. A response is awaited.

Prof McClelland will continue to follow up on progress with Dr Woods and will update PAC on the outcome of these discussions.

Prof McClelland

ii. N. Ireland Cancer Patient Experience Survey 2018

Prof McClelland referred to his communication with the N. Ireland Cancer Network (NICaN) and provided an update on measures which have been taken by the N. Ireland HSC Trusts and BSO (Honest Broker Service), to ensure that the above survey is undertaken in line with COP guidance. Staff from each of the HSC Trusts will assist NICaN with the administration of the survey, thereby ensuring a direct care relationship is in place for accessing and reviewing patient data.

iii. Cerebral Palsy Registry

Prof McClelland and Gillian Acheson provided an update in relation to the ongoing discussions regarding data flows to the N. Ireland Cerebral Palsy Registry. Assurance is being sought by the

HSC Trusts that, as a minimum, adequate information is provided to patients/relatives to advise that some of their information may be passed to the NI Registry to enable it to carry out its important work; to obtain consent where possible; and also to advise on the provision to opt-out of information sharing.

The need for the Registry to demonstrate compliance with GDPR legislation was highlighted. Gillian Acheson advised that assurance will be required from the Registry, prior to the sign-off of Data Access Agreements.

G Acheson advised that an audit had been undertaken within HSC Trusts one year ago in relation to N. Ireland's participation in national audits and work is ongoing to ensure that Trusts are adhering to the requirements for obtaining of adequate patient consent and anonymisation of data flows where possible.

iv. Enterovirus and Human Parechovirus Infections in Children

Prof McClelland referred to advice which PAC had provided to Public Health England (PHE) regarding N. Ireland's participation in the above national research study.

The absence of consent and of equivalent Section 251 legislation in N. Ireland had posed confidentiality issues in the transfer of N. Ireland data to this research study.

Discussion had taken place between PAC, PHE and the Research Lead, regarding the potential options to enable data linkage, to facilitate N. Ireland's participation in this research study, without breaching patient confidentiality.

This discussion had highlighted important issues associated with data linkage for research purposes, in the absence of patient consent, particularly when access to historical data is requested.

5. NI Confidentiality Code of Practice – GDPR Compliance

At the request of the Department of Health, PAC had undertaken a review of the existing Code of Practice on Protecting the Confidentiality of Service User Information (COP) and had formally written to Departmental colleagues in October 2017 to advise that, based on the existing evidence available at that time, PAC were of the opinion that the COP would be compliant with the new GDPR legislation which is due to be implemented in May 2018.

Since then PAC has been able to access additional information and updates on GDPR legislation, which have been made available from various sources, including the Information Governance Alliance (IGA), the ICO, HRA and the Article 29 Working Group. PAC remain of the opinion that the existing COP will be compliant with the new GDPR legislation and will not require a major review, but minimal updates only.

In terms of the quality and breadth of advice provided to users from within health and social care, PAC consider the existing COP to be a valuable document, which compares well to other recently updated guidance.

Following the implementation of the GDPR legislation in May 2018, Prof McClelland advised that PAC will again write to Departmental colleagues, to provide an update on compliance of the COP with the new legislation.

Prof McClelland

6. HSC (Control of Data Processing) Act 2016 – Code of Practice

The HSC (Control of Data Processing) Act, will require the Department of Health to establish a process and an oversight body; and to prepare and publish a Code of Practice (COP) on the processing of information.

PAC had previously highlighted the benefits of the existing COP as a source of guidance for the entire HSC family and therefore would advocate that the new COP would incorporate the content of the existing and that only one COP exist. The new COP would include guidance on the requirements of the common law duty of confidentiality, as well as the legal requirements associated with the new legislation.

Prof McClelland advised that PAC have considered how this might be achieved and over the past months have had discussions regarding possible structures and core content of a new Code, focusing on the interface area between the present Code and a Code under the new legislation. The interface area relates to the uses of service user information for secondary purposes. PAC shared with Departmental colleagues a draft Code, covering the interface area as Chapter 3, revised and updated, and a new Chapter 4. PAC would recommend that the remainder of the existing Code would be incorporated within the new.

PAC again emphasised the need for an appropriate public awareness campaign, in relation to the new legislation, to advise members of the public on how their personal data may be used.

PAC also reiterated the requirements to enable members of the public to 'opt-out' of their information being shared as well as the need for clear guidance/processes on how to request this.

La'Verne Montgomery welcomed PAC's views and the draft COP, with the proposal to incorporate the existing COP into the new. It was acknowledged that much work is yet to be undertaken with regards to the new legislation, drafting of regulations and preparation of a new COP.

7. NI Confidentiality Code of Practice Update Proposal

Given the requirement for a new COP, in line with the new HSC (Control of Data Processing) Act (Northern Ireland) 2016, as well as the forthcoming GDPR legislation, both PAC and Departmental colleagues, agreed that the existing COP requires updating. This would not be a formal review of the document, but would be an interim, in-house update only, in light of Departmental changes and GDPR. A preface would be included to advise that this is an interim measure, prior to introduction of the new legislation and its new Code.

PAC agreed to undertake this interim review and to forward to the Department of Health for sign-off.

PAC

8. Development of Regulations – The Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016

La'Verne Montgomery provided an update on progress in relation to the development of regulations for the implementation of the HSC (Control of Data Processing) Act NI 2016.

The Department of Health will seek to engage further with all relevant stakeholders, including PAC, following the initial informal consultation process undertaken in 2017, and will aim to ensure that the process is as open and transparent as possible.

Consultation has already taken place with the NI Cancer Registry, including discussion on the provision for opt-out.

L Montgomery noted that her colleagues within the Department of Health are also considering the requirements for sharing of identifiable information in the event of a public health emergency. Work is progressing as far as possible, pending Ministerial appointment.

9. Information Governance Report

La'Verne Montgomery provided an update in relation to Information Governance:

- A programme of regular engagement is ongoing with Information Asset Owners (IAOs);
- Colleagues within the Information Management Branch (IMB) continue to focus on preparation for the implementation of the new GDPR legislation in May 2018, with provision of regular updates to civil service staff, as well as provision of updates on progress to the wider HSC;
- Two Data Protection Officers (DPOs) have recently been appointed within the Department of Health, which may be reviewed post GDPR implementation;
- The current vacancy within the Information Management Branch in relation to leadership on secondary uses legislation has been highlighted and it is hoped that a new appointment to this role will be made soon;
- Work is ongoing in relation to Data Privacy Notices and Impact Assessments;
- The appointment of DPOs within the HSC is ongoing. The Department are working with colleagues in BSO to consider how best to appoint DPOs proportionately within smaller HSC organisations, including GP practices. Communication has taken place between primary care colleagues within the Department and the BMA. Consideration is being given to the possible appointment of DPOs for GP practices at scale, for example through the GP Federation.

La Verne Montgomery agreed to request an update on progress on this issue from Mark Lee, her Departmental counterpart within primary care.

Prof McClelland highlighted the need to ensure that Personal Data Guardians within primary care, were identified and that adequate training provision was in place. It was queried whether the

HSCB could assist with this provision.

10. Personal Data Guardians – Training, September Meeting

The annual PDG training is scheduled for 25th May 2018.

The joint meeting of the PAC with PDGs is scheduled for Thursday, 13th September 2018 – the agenda for which will be agreed over the next few months.

11. Any Other Business

PAC Meeting with IGAG

Prof McClelland referred to the PAC's ongoing communication with Information Governance Leads within the HSC Trusts, who frequently contact PAC to seek advice on data protection/confidentiality issues.

It was agreed to have further meetings of PAC members with members of the Information Governance Advisory Group (IGAG). Prof McClelland to discuss with Gillian Acheson and Sharon Anderson.

Prof McClelland / Gillian Acheson

Department of Health and HSC Protocol for Sharing Service User Information for Secondary Purposes

It was noted that the above protocol was last reviewed in 2011 and requires updating, the responsibility for which sits with Personal Data Guardians. Prof McClelland agreed to table this for discussion at the joint meeting with PDGs in September.

Prof McClelland

Department of Health - Strategic Information Group

La'Verne Montgomery advised that the Department of Health had recently established a Strategic Information Group (SIG), co-chaired by the Department of Health, and the Health & Social Care Board (HSCB). This group has replaced the previous Regional Information Group (RIG). An initial meeting had been held and the Terms of Reference are yet to be agreed. It is expected that IGAG will provide information governance input to this strategic group.

Ms Montgomery would attend future meetings of this Group and agreed to update PAC on developments and to forward the membership and Terms of Reference, once agreed.

12. Dates for 2018 Meetings

- Wednesday, 27th June 2018
- Thursday, 13th September 2018 (Joint Meeting with PDGs)
- Wednesday, 21st November 2018