

# 51<sup>st</sup> Meeting of the Privacy Advisory Committee

Wednesday, 24<sup>th</sup> January 2018 at 10:00am

Venue: Meeting Room, Postgraduate Centre, Belfast City Hospital

## AGENDA

**Present:** Prof Roy McClelland (Chair), Prof Brice Dickson, Dr Colin Harper, Dr Michael McKenna, Gillian Acheson, Geraldine Reynolds

**In attendance:** Charlene McQuillan (Information Management Branch, Department of Health)

### 1. Apologies and Welcome

Apologies were received from Dr Clodagh Loughrey.

Prof McClelland welcomed Gillian Acheson, Information Governance Manager, Belfast HSC Trust, who had been invited to join the Privacy Advisory Committee to provide guidance and expertise in relation to information governance.

Prof McClelland advised that John Growcott had stepped down from his role on PAC and that he would write to him to extend thanks for his valuable input to the Committee over the last number of years. He also agreed to follow up on a replacement representative on the Committee from within social care.

**Prof McClelland**

Prof McClelland also welcomed Charlene McQuillan, Information Management Branch, Department of Health.

### 2. Minutes of the Previous Meeting ~ 21st June 2017

The minutes of the 50<sup>th</sup> meeting of the PAC held on 21<sup>st</sup> June 2017 were agreed.

### 3. Matters Arising:

#### i. Joint meeting PAC and PDGs (13th September 2017)

PAC had held its annual joint meeting with Personal Data Guardians on 13<sup>th</sup> September 2017. Sandra Lomax, Deputy Chair of the UK Caldicott Guardian Council (UKCGC), had been in attendance.

It was proposed that a digital forum be established to support the NI PDGs, similar to those which are already in place in other parts of the UK. It was agreed that this would be a valuable support network and source of guidance to PDGs in undertaking their role.

Subsequent to the joint meeting, Dr Chris Bunch, Chair of the UKCGC, had written to PAC, inviting PDGs to join the UKCGC online digital forum, and had offered assistance from the UKCGC in establishing a local NI regional network. A member of the NI PDGs is also invited to attend future UKCGC meetings, which are held bi-monthly in London.

Prof McClelland advised that he had discussed the above proposals with Dr Paddy Woods, PDG/deputy CMO, who had agreed to raise the issue at the next meeting of the NI Medical Leaders Forum.

Prof McClelland agreed to contact Dr Woods for an update on progress.

**Prof McClelland**

## **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 agreed to raise the issue for discussion at the forthcoming meeting of the Medical Leaders Forum, to consider how the issue could be addressed.

Prof McClelland will continue to follow up on progress with Dr Woods – item to remain on the agenda.

**Prof McClelland**

## **iii. Information Governance Advisory Group (IGAG)**

Prof McClelland referred to the proposal at a recent meeting of IGAG, that PAC meet with this group on an annual basis, similar to the existing arrangement with PDGs.

Prof McClelland noted that as Gillian Acheson is now a member of PAC and attends IGAG meetings, this would provide a link between both forums.

Prof McClelland and G Acheson to discuss further and to consider if it would be beneficial for a meeting of PAC and IGAG to be arranged.

**Prof McClelland / G Acheson**

## **4. Chairman's Update**

### **i. Regional Mortality & Morbidity Review System**

Prof McClelland referred to the most recent letter of advice sent from PAC to Dr P Woods, Department of Health, regarding Death Certification and the Regional Mortality & Morbidity Review System (RM&MRs), 21<sup>st</sup> October 2017 (as circulated).

PAC had previously outlined concerns regarding the potential risks associated with the use of HSC e-mail for dissemination of alerts to Consultant staff and others, who had been involved in the direct care of a recently deceased patient. PAC had advised that reports of the M&M meetings should be accessed via the NIECR and should not be circulated within the HSC e-mail system, which may not be secure. Any circulation of M&M reports beyond the NIECR, for the purposes of shared learning, should be in an anonymised form.

PAC had also advised that the public should be informed that their information may be reviewed and disclosed as part of the RM&MR process. Work is ongoing to include such information regarding the RM&MR process, within HSC Trust patient information packs made available at the time of patient admission; and within consent documentation.

PAC had also highlighted that although patient data is included within death certification and therefore already within the public domain, the information is sensitive and should be treated accordingly.

There was some discussion regarding the application of the 'opt out' wishes of a patient and it was queried whether this would extend and need to be respected after death. It was agreed that this may need to be considered further in the drafting of regulations in relation to the HSC (Control of Data Processing) Act. Charlene McQuillan agreed to raise with relevant colleagues within the Department of Health.

**Charlene McQuillan**

## **ii. Intensive Care National Audit & Research Centre Data Flows**

Prof McClelland referred to the communication which had been forwarded by Dr P Woods in relation to ongoing discussion with the Intensive Care National Audit & Research Centre (ICNARC); and the involvement of N. Ireland in two 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, there is a need to ensure the secure transmission of data. Dr Woods had participated in a teleconference with ICNARC in early November 2017, when options to ensure this safe data transfer had been discussed, including the potential adjustment of data requirements and pseudonymisation of information. Discussion is ongoing. Dr Woods will update PAC on progress.

The issue will also be discussed at the next meeting of the Medical Leaders Forum and the Department of Health will issue guidance to Trusts on how to proceed.

## **5. NI Confidentiality Code of Practice and GDPR [Enc 3]**

The Department of Health had asked PAC to review the existing Code of Practice on Protecting the Confidentiality of Service User Information (2012), to check compliance with the forthcoming GDPR legislation, which will come into effect in May 2018. Prof McClelland referred to the PAC's letter of response to Lynne Curran, Head of Information Management Branch, 31<sup>st</sup> October 2017, advising that, based on existing evidence, the COP should be compliant with GDPR legislation. However, PAC will review any new guidance from the Article 29 Working Group, ICO, NHSE and HRA, over the coming months and will provide a further update to the Department, prior to May 2018.

There was some discussion in relation to the implications of the new GDPR legislation regarding consent and the secondary use of information eg: for research purposes. It was agreed that in any future review of the existing COP, it may be useful to provide guidance via the use of 'scenarios'.

## **6. NI Confidentiality Code of Practice and GMC Confidentiality Guidance**

Prof McClelland advised that, on behalf of PAC, he had undertaken a review of the existing COP, in line with the revised GMC confidentiality guidance, which came into effect in April 2017. It was agreed that whilst there are elements of the existing COP which do require updating, in terms of the quality and breadth of advice provided to users from within health and social care, the COP is considered to be a valuable document, and compares well to the revised GMC guidance.

It was agreed that any future revision of the existing COP should emphasise the benefits of the use of anonymised/de-identifiable data, in relation to the secondary use of information.

## **7. NI Confidentiality Code of Practice and HSC (Control of Data Processing) Act [Enc 4]**

It was noted that the HSC (Control of Data Processing) Act, will require the Department of Health to establish a process and an oversight body, to enable the use of identifiable health and social care information, for prescribed health and social care purposes which are in the public interest; and to prepare and publish a Code of Practice on the processing of information.

PAC would advocate that the new Code of Practice (COP) would incorporate the content of the existing Code of Practice on Protecting the Confidentiality of Service User Information and that only one COP exist - to include guidance on the requirements of the common law duty of confidentiality, as well as the legal requirements associated with the new legislation.

PAC would expect that the target audience of the new COP would be the same as that for the existing ie: Consultants, Information Governance Leads, Senior Social Workers, Research Leads etc. and therefore, the level and detail of content should reflect this.

PAC also felt that additional Guidance Notes would need to be included within the content of the application forms to be submitted to the oversight Committee, to ensure that the application process for those within the research community is easily accessible and as straightforward/user-friendly as possible – this would be preferable to including this level of detail within the actual COP.

The benefits to the research community of adequate sign-posting/reference to the new N. Ireland oversight body, within the HRA website, were highlighted.

PAC would also advocate the provision of an appropriate information campaign to advise members of the public on how their personal data will be used.

PAC also stressed that the new Code of Practice would need to be in place prior to the establishing of the oversight body.

Prof McClelland had prepared a draft outline of the proposed content and format of a new COP, which had been shared with PAC, and he would update this document to reflect discussion. He agreed to write to La’Verne Montgomery, Head of Information Management Branch, Department of Health, to formally document PAC’s recommendations regarding the content of the new COP. Charlene McQuillan also agreed to update Departmental colleagues on discussion.

**Prof McClelland/Charlene McQuillan**

#### **8. Patient Participation in Research [Enc 5]**

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 significantly informed by the Code of Practice on Protecting the Confidentiality of Service User Information, as well as the revised GMC guidance on confidentiality.

Further to discussion at the joint meeting of the PAC with Personal Data Guardians in September 2017, Prof McClelland had prepared a separate document providing guidance in relation to the role of the Research Nurse within the generic HSC/hospital setting. It was agreed that this Advice Note should be shared with members of the Information Governance Advisory Group (IGAG). Prof McClelland agreed to forward to Charlene McQuillan, for onward circulation to this Group.

**Action: Prof McClelland / Charlene McQuillan**

Prof McClelland also agreed to forward the original Advice Note in relation to the primary care setting, to Dr Margaret O’Brien, Assistant Director of Integrated Care, HSCB, to highlight its existence and to request guidance on how this document could best be shared with colleagues within primary care.

**Action: Prof McClelland**

**9. Development of Regulations - The Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 ~ Charlene McQuillan**

Charlene McQuillan, Information Management Branch, Department of Health, provided an update on the Health and Social Care (Control of Data Processing) Act. The primary legislation received Royal Assent in April 2016. Since then work has been ongoing in relation to the development of operational policy proposals and accompanying regulations.

Work is progressing as far as possible, pending Ministerial appointment.

A program of informal engagement with relevant stakeholders had taken place during the summer of 2017, in relation to the development of policy and regulations, in preparation for a formal public consultation process, which is yet to be approved.

A paper has been drafted and forwarded to La'Verne Montgomery, Head of Information Management Branch, Department of Health.

It is expected that within the existing timeframe, legislation will not be in place until 2019-2020.

**10. Information Governance Report ~ Charlene McQuillan**

Charlene McQuillan provided an update on Information Governance, the main focus of which has been in relation to preparation for the implementation of the new General Data Protection Regulation (GDPR), which will come into effect in May 2018.

**11. Any Other Business**

**New Chair of Confidentiality Advisory Group (CAG)**

Prof McClelland advised that Tony Calland had recently replaced Mark Taylor as Chair of the Confidentiality Advisory Group (CAG).

**Government Response to the National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs and the Care Quality Commission's Review 'Safe Data, Safe Care'**

Prof McClelland referred to the above document, which had been circulated for review. PAC were asked to submit any individual comments to Prof McClelland, who would then provide feedback on the response document, on behalf of PAC, to Sharon Anderson, Information Management Branch, Department of Health.

**12. Dates for 2018 Meetings**

- Thursday, 12<sup>th</sup> April 2018
- Wednesday, 27<sup>th</sup> June 2018
- Thursday, 13<sup>th</sup> September 2018 (Joint Meeting with PDGs)
- Wednesday, 21<sup>st</sup> November 2018

**13. For information – PAC Annual Report to DoH [Enc 6]**

Prof McClelland referred to the PAC's Annual Report ~ 2017, which had been forwarded to colleagues within the Department of Health.