

49th Meeting of the Privacy Advisory Committee

Wednesday, 11th January 2017 at 10:00am

GMC Office, 9th Floor, Bedford House, 16-22 Bedford St, Belfast BT2 7FD

MINUTES

Present: Professor Roy McClelland (Chair)
Dr Michael McKenna, BMA NI Representative to PAC
Professor Brice Dickson
John Growcott
Dr Colin Harper
Dr Clodagh Loughrey
John Millar
Geraldine Reynolds

1. Apologies

Apologies were received from Grace Irwin.

2. Minutes of the Previous Meeting ~ 22th June 2016

The minutes of the previous meeting held on 22nd June 2016 were agreed.

3. Matters Arising:

i. Joint PAC and PDG Meeting – Wednesday, 14th September 2016

The joint meeting of PAC with Personal Data Guardians (PDGs) had been held on Wednesday, 14th September 2016 and had been well attended.

Dr Brendan O'Brien, Chair of the Honest Broker Governance Board (HBGB) had delivered a presentation, providing an update on progress in relation to the Honest Broker Service (HBS) as well as the ongoing work of the HBGB.

At the meeting it was noted that Information Governance Leads are currently experiencing similar pressures and challenges to PDGs in relation to data control and sharing, particularly in relation to secondary uses of information, in the absence of legislation similar to Section 251 in England and Wales, eg: requests for N. Ireland participation in national research projects. It was agreed that IG Leads may benefit from the opportunity to meet with PAC to discuss some of these issues. Prof McClelland had since contacted John Millar, Department of Health, who chairs a regional IG Leads Forum to see if IG leads would like to meet with PAC. Prof McClelland and J Millar to follow up on this.

Action: Prof McClelland / John Millar

Concern regarding the absence of formal PDG training for GPs had also been raised at the joint meeting.

Dr Michael McKenna felt that there was a significant gap in the provision of PDG training for GPs and believed that the provision of such training would be very timely and welcomed within the primary care setting.

Data Guardians are in place within the 347 GP practices.

There was some discussion regarding how PAC could facilitate such training and the

options for delivery, including on-line training provision and/or the organisation of a formal event.

It was agreed that the imminent release of the revised GMC confidentiality guidance could present the opportunity to progress the issue with GPs. Other matters of interest for discussion with GPs could include developments in relation to the new legislation governing secondary uses of patient information and the Research Nurse Network *etc.*

Dr McKenna advised that he had also been in discussion with Margaret O'Brien, Health & Social Care Board (HSCB), in relation to the improved education of GPs with regards to their responsibilities in terms of confidentiality/data protection *etc.* Prof McClelland and Dr McKenna to discuss further.

Action: Prof McClelland / Dr M McKenna

**ii. Access Research Knowledge (ARK) Seminar: 7th September 2016
Public Attitudes to Data Sharing in N. Ireland ~ Findings of the N. Ireland Life & Times Survey 2016**

Prof McClelland and Dr Colin Harper had attended the Access Research Knowledge (ARK) Seminar held on 7th September 2016 regarding public attitudes to data sharing in N. Ireland. The findings of the N. Ireland Life & Times 2016 Survey had been presented. Prof McClelland had spoken at the event ~ a summary paper was circulated to PAC.

The survey findings show a high level of trust invested by the N. Ireland public in healthcare professionals providing direct care. The survey also reports a high level of public interest in the potential benefits of their health information being used for health & social care research, however findings had highlighted significant concerns around issues of data control and security.

The survey findings illustrate public goodwill to achieve potential benefits from research, however there is a strong acknowledgement of the individual's right to privacy. The overwhelming majority of respondents (83%) agreed that the right to privacy has to be respected above everything else. At the same time, a similar number of respondents (85%) agree that if personal identifiable data can be anonymised and the individual's right to privacy is maintained, then the data should be used, where there is a potential benefit to society.

Prof McClelland welcomed the survey findings, which are of great interest and very useful in informing the future work of PAC.

iii. GMC Review of Confidentiality Guidance

PAC had formally responded to the GMC consultation on the review of its confidentiality guidance in 2016. The revised guidance is due for release at the end of January 2017.

It was agreed that it would be a worthwhile exercise for PAC to undertake an in-house review of the existing DHSSPS Code of Practice on Protecting the Confidentiality of Service User Information (COP), last updated in January 2012, in line with the revised GMC confidentiality guidance. The findings of this in-house review of the document, against the new GMC guidance, will assist in informing PAC and DHSSPS and indicate where the COP may require updating. Prof McClelland agreed to initiate this review on

behalf of PAC.

Action: Prof McClelland

It was also noted that the existing COP should be informed by the new N. Ireland legislation (Control of Data Processing Act), as well as the recently released National Data Guardian for Health & Care (Caldicott) Review on Data Security, Consent and Opt-outs.

iv. NHS Blood and Transplant Application

Prof McClelland advised that he was still in communication with Dr Paddy Woods, Deputy CMO, DHSSPS, regarding the work of the NHS Blood & Transplant staff who are involved in the collection of potential donor audit information from N. Ireland patient data. No further update on progress at this time. Item will remain on this agenda.

4. Chairman's Update

i. National Data Guardian Report ~ Review of Data Security, Consent and Opt-outs

Prof McClelland referred to the recent National Data Guardian for Health & Care Review of Data Security, Consent and Opt-outs.

The DHSSPS had undertaken a public consultation on this latest review, which closed in September 2016, to which PAC had submitted a formal response (copies circulated). It was highlighted that there is still much work to be done to instill public confidence in data sharing for secondary purposes.

One of the key recommendations of the latest review, is that the public should be given the opportunity to 'opt-out' of the sharing of their data for secondary uses. It was noted that Macmillan Cancer and Cancer Research UK had undertaken a review to define a new approach to informing patients about cancer registration and a report has subsequently been produced. The obligation on all HSC Trusts to inform patients of their ability to opt-out of their information being shared on cancer registries was highlighted.

Prof McClelland advised that he had a recent discussion with Dr Anna Gavin, Chair of the N. Ireland Cancer Registry, regarding the issue of obtaining patient consent and the provision of an opt-out facility for patients.

John Millar advised that his colleagues within the Department of Health were following up with counterparts in England regarding the outcome of the consultation re Caldicott 3 proposals. The consultation exercise closed in September 2016.

He advised that work is continuing in relation to the implementation of the EU General Data Protection Regulations (GDPR) in N. Ireland, due for implementation in May 2018. He noted that there has been increased emphasis on the provision of 'opt-out' for patients, with regard to the sharing of their personal data. PAC agreed that a more pro-active approach needs to be taken in obtaining patient consent, as opposed to assuming consent.

ii. Honest Broker Service and ECR

Prof McClelland noted that he had been invited to a meeting with Mrs Karen Bailey, Director of Customer Care & Performance, Business Services Organisation, regarding the Honest Broker Service (HBS).

Dr McKenna advised that he had attended this meeting, in his capacity as a member of the NIECR Governance Board, chaired by Dr Jimmy Courtney, and provided an update on discussions.

Access to patient information via the NIECR, by those with an existing direct care relationship for the purposes of clinical audit had taken place.

He noted that in the various scenarios of data access which had been discussed, express consent had been obtained from patients and therefore access was considered to be reasonable and in keeping with the content of the recent Caldicott review.

It was highlighted that there is a fine balance between the duty to use patient data for research/public benefit, along with the need to maintain patient confidentiality – patients may opt out of the sharing of their data for research/audit purposes if they lose confidence in how their information is being shared.

Dr McKenna will provide feedback to PAC on the outcome of future meetings.

5. Research Nurse Network

- i. Letter from Professor Ian Young, Director of R&D; and*
- ii. Discussion with Dr Siobhan McGrath Head of OREC NI*

Prof McClelland referred to the documentation circulated to PAC in advance of today's meeting in relation to the N. Ireland Research Nurse Network (RNN) – including the letter received from Prof Ian Young, Director of HSC Research & Development, Public Health Agency, (21 November 2016), following their recent meeting. His subsequent e-mail communication with Siobhan McGrath, Head of the Office for Research Ethics Committees N. Ireland (ORECNI) had also been circulated to PAC.

Prof McClelland provided an overview on the discussions which had taken place with both Prof Young and ORECNI to date.

The Research Nurse Network in N. Ireland is provided by the R&D Office, with Research Nurses appointed within the Belfast HSC Trust. The issue of concern is that in a number of GP practices in N. Ireland, contractual arrangements had been in place, permitting the Research Nurses to access patient records in order to identify those patients who may be suitable to participate in specific research projects. The concern arises in that the Research Nurses are accessing patient records, even though they are not a member of the direct care team and therefore do not have a direct care relationship with the patients.

Prof Young had sought the advice of PAC on a specific proposal in relation to allowing the Research Nurses access to patient records. The proposal centered on a letter to be sent to all patients in a participating practice informing them, among other things, of the role of the RNN and providing the option of opt-out.

There was lengthy discussion on the matter, including:

- A lawful basis for accessing patient information by Research Nurses;
- The guidance within the Code of Practice on Maintaining the Confidentiality of Service User Information;
- The recent findings of the N. Ireland Life & Times Survey on Public Attitudes to

Data Sharing were highlighted – ie: the strong public endorsement of the need for the ‘right to privacy’ to be respected above everything else. Public confidence in how their personal information is stored and shared is critical;

- The current absence of statutory regulations governing the secondary use of data in N. Ireland, similar to Section 251 in England and Wales, was noted. Although the HSC Control of Data Processing Act had received Royal Assent in April 2016, an interim solution is still required in the absence of both regulations and a Statutory Committee to oversee data processing for the secondary use of information;

- In order to inform discussion, Prof McClelland provided PAC with an overview of an extract from the GMC’s revised confidentiality guidance (due for publication soon) on the process of anonymising of information and public interest disclosures for health and social care purposes;

The PAC will continue to provide advice to health and social care bodies regarding the use of patient information, in the absence of current N. Ireland legislation;

- It was noted that the provision of an ‘opt-out’ for patients, cannot be interpreted as ‘patient consent’;

- The disclosure of information in the case of ‘over-riding public interest’;

- It was noted that the Research Nurses are professionals who will have a contract with a HSC Trust in N. Ireland and who would be expected to adhere to a professional code of conduct;

- Other issues noted :

- the ability for Research Nurses to access all detail in a patient’s record;
- the practicality of alternative arrangements;

- It was agreed that alternative options for the identification of suitable research participants within the primary care setting should be further explored, including:

- the possibility of using technology to undertake an initial anonymised review of patient data, to identify a pool of patients, who may then all be contacted by their Practice to seek their consent for the Research Nurses to access their records to determine if they are indeed suitable participants for specific research projects;

- The possibility of the Research & Development Office funding individual GP practices for their own staff (with a direct care relationship) to undertake the initial review of patient records to identify suitable research participants;

- The potential appointment of Research Nurses, within the N. Ireland GP Federation model – similar to the existing arrangements for GP based Pharmacists, already in place within primary care;

- It was agreed that Prof McClelland and Dr McKenna should further discuss alternative proposals. Prof McClelland advised that he had been invited to attend a further meeting with the R&D Office and others to discuss the Research Nurse Network and would seek Dr McKenna’s input to future discussions;

- Ultimately, the decision on whether or not disclosure of information is in the public interest and therefore ‘lawful’ can only be decided by the courts;

- It was agreed that this is a complex area, which merits further discussion.

Prof McClelland agreed to draft a formal response to Prof Ian Young on behalf of

PAC, subsequent to further discussions with the R&D Office and ORECNI.
Prof McClelland to update PAC on outcome of further discussion;

- Prof McClelland also agreed to contact Mark Taylor, Chair of the CAG, to seek further detail on the processes in place for the approval of research applications in England and Wales and to request specific examples of applications which had been granted CAG approval.

Action: Prof McClelland

iii. Correspondence re Opt-in for Data Sharing ~ Frank Sullivan

Prof McClelland referred to the above article 'Opt-in Method is Vital for Data Sharing' circulated to PAC for information.

The article outlines an 'opt-in' mechanism for the sharing of health data for research purposes.

6. Research Study re Suicide in Children and Young People

Prof McClelland referred to his recent communication with Damian Houston, Information Governance Manager, Western HSC Trust, (5th December 2016) regarding N. Ireland participation in a national research study into suicide in children and young people.

Mr Houston had sought the advice of PAC, on behalf of the Information Governance Network Group for the HSC Trusts in N. Ireland, with regards to anonymisation/pseudonymisation of data to allow N. Ireland HSC Trusts to participate in such national research studies. HSC IG Leads are increasingly receiving requests to enable data flows from N. Ireland for participation in such national research studies and there have been issues surrounding this, in the absence of consent and Section 251 equivalent legislation currently in N. Ireland.

Prof McClelland advised that he would also participate in a tele-conference with IG Leads to discuss further during the following week.

7. HSC (Control of Data Processing) Act

John Millar provided an update on progress regarding the HSC Control of Data Processing Act. Primary legislation received Royal Assent in April 2016.

Work is ongoing within DHSSPS on the development of operational policy proposals and regulations.

It is expected that a two-stage approach will be implemented. Prior to a formal public consultation exercise on proposals, initial engagement will take place with relevant stakeholders to work through the finer detail of the policy proposals and recommendations to Minister.

PAC will be consulted in due course.

It is expected that it will be well into 2018 before formal regulations/legislation is in place.

Prof McClelland queried if the N. Ireland Cancer Registry would be subject to the same controls/regulations as other organisations with regards to processing/sharing of personal identifiable data or if it is intended that the Cancer Registry should be given specific support within the new legislation. PAC would be of the view that no one organisation should be subject to exemptions or specific support to any other in

N. Ireland. J Millar clarified that there was no specific reference to the N. Ireland Cancer Registry within the primary legislation but that commitments may have been given during the scrutiny by the Health Committee.

Prof McClelland referred to the recent Caldicott report, which highlighted the need for organisations to enhance the level of consent taking for disease registries, by contacting patients directly where appropriate, at the point of registration.

8. Information Governance Report

John Millar advised that the EU General Data Protection Regulations (GDPR) will officially come into effect in May 2018 and implementation is continuing to be managed as a N. Ireland Civil Service wide project.

He advised that the N. Ireland Information Commissioner's Office are currently delivering presentations and facilitating discussion within HSC organisations, regarding the implementation of GDPR in N. Ireland.

9. Any Other Business

Code of Practice on Protecting the Confidentiality of Service User Information:

Prof McClelland referred to the DHSSPS Code of Practice on Protecting the Confidentiality of Service User Information, last updated in 2012, which under the terms of reference of PAC, would normally be due for review.

However given the forthcoming implementation of the new legislation within N. Ireland and the requirement therein for a new Code of Practice to be established, Prof McClelland will await direction from DHSSPS on the matter.

As previously discussed, PAC will undertake an in-house review of the existing COP against the GMC revised confidentiality guidance, due for release later this month, the outcome of which should inform PAC on the fitness for purpose of the current document and where updating may need to be considered.

10. PAC Annual Report 2016

PAC's Annual Report for 2016 was circulated for information. Prof McClelland will formally forward a copy of the report to John Millar, for onward circulation to his colleagues as appropriate.

11. Dates for 2017 Meetings

Wednesday, 29th March 2017

Wednesday, 21st June 2017

Wednesday, 13th September 2017 ~ Joint Meeting with Personal Data Guardians

Wednesday, 22nd November 2017