59th Meeting of the Privacy Advisory Committee
Thursday, 18th November 2021 at 11:30am-12:30pm
On-Line Web-Ex Meeting

In Attendance:
Prof Roy McClelland (Chair), Prof Ian Young, Brendan O'Neill, Dr Clodagh Loughrey, Brice Dickson, Colin Harper, Dr Michael McKenna, Gillian Acheson, Eileen McKay

1. Apologies and Welcome

Apologies were received from Geraldine Reynolds.

2. Minutes of the Previous Meeting – 24th June 2021

The minutes of the previous meeting held on 24th June 2021 were agreed.

3. The Role of the Personal Data Guardian

Prof McClelland advised that he had been invited to attend the next meeting of the Medical Leaders Forum on Monday, 22nd November 21, and had requested that the role of the Personal Data Guardian (PDG) be added as an item for discussion. It was however noted that this forum would not include the PDGs who are Executive Directors of Social Work.

Prof Mc Clelland referred to the previous discussion regarding the role of the PDG which had taken place at the January 21 PAC meeting, following which Dr Chris Bunch, Chair of the UK Caldicott Guardian Council (UKCGC), had been invited to join the September 21 joint meeting of PAC with PDGs, to discuss the Caldicott Guardian (CG)/PDG role.

Discussion regarding the role of the PDG followed:

- It was noted that PDGs generally undertake the role for around 3 years;
- PDGs had been advised in advance of the September 21 joint meeting, that discussion would focus on the role of the PDG. However, it was noted that only one of the HSC Trust PDGs had been in attendance, highlighting the difficulty for PDGs in fulfilling their role;
- It was however noted that attendance at annual PDG training has been good.

Gillian Acheson, Information Governance Manager, BHSCT, provided some feedback on the interaction between IG Leads and PDGs within the HSC Trusts;

- In relation to daily operational issues regarding the flow of clinical data (eg: sign-off of Data Access Agreements etc), typically initial discussion would take place with the Trust IG Leads/Directorate Managers, as opposed to approaching PDGs directly. Advice would be sought from PDGs in relation to more prominent IG issues such as sharing of data with National Registries etc;
- Gillian outlined the IG structure within HSC Trusts; it was noted that the role of the SIRO

had become more prominent in recent years; each Trust has also appointed Information Asset Owners (IAOs) at a Directorate level. PDGs would previously have sat on Information Governance Boards, however in general SIROs now undertake this role within the Trusts;

- The implementation of the SIRO and IAO roles, as well as the now statutory requirement for Data Protection Officers (DPOs) within HSC Trusts, has created an established IG structure and reduced the requirement on IG Leads to contact PDGs directly.

- Eileen McKay, Deputy Executive Director of Social Work, BHSCT, provided some additional comments in relation to communication with IG Leads, eg: in the event of data breaches, FOI and research requests etc.
- Brendan O'Neill advised that the Department of Health (DOH) are actively seeking to appoint a Personal Data Guardian in relation to social care, the appointee will work alongside the Deputy Chief Medical Officer.
- Dr McKenna highlighted the requirement for PDGs to be fully aware of the specific information governance detail contained within DAAs etc. and queried whether this was a reasonable demand on PDGs. He also noted the requirement for clinical expertise in fulfilling the PDG role.
- The recent appointment of Chief Clinical Information Officers (CCIO) and Deputy CCIOs, within each of the HSC Trusts, as a requirement of the implementation of the NI Encompass programme, was noted. The CCIO role has been assigned to Lead Clinicians, as well as AHP and Nursing Leads. It was queried whether the appointment of the CCIOs would have an impact on the PDG role and also whether the CCIO role should be assigned to Director level within the HSC organisations, to ensure they had the required authority to influence IG processes/decision-making.
- Prof McClelland referred to the initial definition and requirement of the PDG role, as outlined by the Department of Health (2009) – paper as circulated at joint meeting in September 21, Annex 3 – detail as below;

Annex 3

Key Personal Data Guardians' Responsibilities:

Strategy & Governance: the Personal Data Guardian should champion confidentiality issues at Board level, should sit on an organisation's Information Governance Board/Group and act as both the 'conscience' of the organisation and as an enabler for appropriate information sharing.
Confidentiality & Data Protection expertise: the Personal Data Guardian should develop a knowledge of confidentiality and data protection matters, drawing upon support staff working within an organisation's Information Governance function but also on external sources of advice and guidance where available.
Internal Information Processing: the Personal Data Guardian should ensure that confidentiality issues are appropriately reflected in organisational strategies, policies and working procedures for staff.
Information Sharing: the Personal Data Guardian should oversee all arrangements, protocols and procedures where confidential personal information may be shared with external bodies both within and outside the HPSS. This includes flows of information to and from partner agencies, sharing through ICT systems, disclosure to research interests and disclosure to the police.

- It was emphasised that there has been significant development and progress in relation to information governance, data sharing, technology and legislative requirements within the HSC, since the initial appointment of PDGs and the outline of their key responsibilities.
- The PDG role has been superseded, particularly in relation to Information Governance and technological developments.
- The responsibility on PDGs to act as both the conscience of the organisation and enabler for appropriate information sharing, requires an in-depth knowledge and for PDGs to keep up to date on a wide range of IG issues - it was queried whether this is feasible.
- The requirement on PDGs to act as enabler for data sharing was also emphasised and is considered to be an important aspect of the role. PDGs need to have a clear understanding and appreciation of the benefits to data sharing, as well as to the safeguarding of data – it was queried whether the balance between the two was in place and achievable.
- In summary, concern was raised as to whether Medical Directors/Executive Directors of Social Work, are best placed to undertake the PDG role, given the requirements for both clinical expertise and an understanding of the wide-ranging and rapidly developing IG issues and the amount of time required to fulfil this role, given the competing demands and pressures within the HSC.

- The role of the PAC in providing advice and guidance on confidentiality issues within the HSC was highlighted, the existing Committee membership has a wide range of expertise. PAC receives a large volume of requests for advice on confidentiality issues, including from the HSC Trust IG Leads and could therefore be considered to be a regional PDG.
- There was discussion on whether the existing HSC IG structures would be impacted by the absence of PDGs and whether there is currently a statutory requirement for HSC organisations to have a PDG in place.
- PAC has advocated that the new Advisory Committee, which is to be implemented in line with the new NI legislation, undertake a similar role to the existing PAC, as well as fulfilling legislative requirements.
- B O'Neill referred to recent IG developments, including the role of the Chief Digital Information Officer, as well as the impact of the implementation of the Encompass Programme within the HSC – encompass will link information across primary, secondary, community and social care.
- GDPR implementation and the introduction of the DPO role were also noted. The DPO has reduced the level of responsibility on PDGs in terms of data protection/IG issues.
- In general it was considered that there is not currently a great deal of overlap between the PDG and the IAO/DPO role.

  The PDG role is to provide support and advice within HSC organisations, acting as the 'conscience'; responsible for challenging decision-making;

  The IAOs, which currently sit at Co-Director level within the Trusts, along with DPOs, currently provide support, with the provision of regulatory advice.
- It was queried whether PDGs were able to challenge decision-making within their

organisations, if they are not involved in daily operational discussions.

Prof McClelland thanked PAC for the informative discussion, prior to his attendance at the Medical Leaders Forum on 22 November, where it is hoped PDG views on the issue can be obtained. Prof McClelland advised that a joint meeting between PAC with PDGs would be scheduled for early in 2022.

Prof McClelland

Prof McClelland noted that although PAC were not required to undertake a review of the role of PDG, it was within PAC's remit to report back to the DOH on the matter and raise any concerns/recommendations for the future role of PDG.

Brendan O'Neill agreed to follow up with Departmental colleagues as to the current remit/appointment of PDGs.

Brendan O'Neill

4. Any Other Business:

i. Advice regarding the Breast Implant Register& Patient Consent and change of circumstances ~ Brendan O'Neill

There was further discussion regarding the Breast & Cosmetic Implant Register (BCIR). Brendan O'Neill referred to the circulated summary paper which had been provided by David Wilson, DOH, along with additional papers in relation to the consent process, including the BCIR Patient Consent Form and Patient Information Leaflet for NI patients.

Further to previous discussion on the issue, PAC was of the opinion that although the BCIR is considered to be an extension of a patient's direct care record, eg: to facilitate tracing of patients in the event of a product recall or safety concerns, the data is collected and held by NHS Digital and patients would not normally expect their data to be held outside of N. Ireland. Therefore, PAC had considered that explicit consent should be sought for data to be held on the BCIR, as well as for the potential secondary processing of patient data (data may be used to identify any trends/complications related to the use of specific implants).

Brendan O'Neill advised that feedback obtained from the NI HSC Trusts had raised concern, that in seeking explicit consent from patients for their data to be held outside of NI, this raises the possibility of a patient withholding or later withdrawing consent. There was concern that direct care may be compromised and could lead to patient safety issues.

It was also queried whether NHS Digital had the functionality to enable the withdrawal of patient consent.

DOH had since proposed that the BCIR Patient Information leaflet and Consent Form be amended to make clear that the patient is informed that part of their direct care record is to be held on the NHS Digital Registry, and that consent is only sought for any secondary processing of patient identifiable data.

There was some further discussion regarding the distinction between the legislative requirements/powers for the *collecting* of data and any subsequent *processing* of data.

B O'Neill referred to recent UK legislative developments and the recent Health & Social Care Bill, recently given royal assent, which will enable the UK-wide collection of data (legal power to collect, however not to process NI data). It was noted that the BCIR leaflet had been drafted prior to this legislative development.

The parallels with NIECR and consent and what will happen with the implementation of the encompass system were also noted. It was highlighted that the encompass programme will allow for greater controls over how patient data is used for primary and secondary purposes.

It was agreed that it would be of benefit to make reference to the legal basis for the collecting of data within the BCIR Patient Information Leaflet and Consent Form, for both direct care and also any secondary use of information.

Further to the recent UK legislative developments and the evolving situation in terms of patient consent, it was agreed that it would be of benefit for PAC to discuss the issue further with David Wilson, DOH, prior to any formal recommendation from PAC.

4. Dates for 2022 Meetings of PAC

Dates for 2022 PAC meetings to be confirmed.