60th Meeting of the Privacy Advisory Committee
Thursday, 20th January 2022 at 11:30am
Microsoft Teams Meeting

1. **Apologies and Welcome**

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

   Apologies:
   Dr Michael McKenna

2. **Minutes of the Previous Meeting –** 18th November 2021
   The minutes of the previous meeting held on 18th November 2021 were agreed.

3. **Matters Arising:**

   i. **The Role of the Personal Data Guardian / Medical Leaders Forum, 22nd November 2021**

   Prof McClelland advised that further to discussion at the November PAC meeting regarding the role of the PDG, he had attended the Medical Leaders Forum on 22 Nov 21 to discuss the issue.   Only one Medical Director/PDG had joined the meeting and discussion had been limited.   An informal meeting of Medical Directors had since been scheduled for 14th February 2022, to which Prof McClelland had been invited to discuss the PDG role.

   Colin Harper, as Deputy Chair of PAC, will join Prof McClelland at this meeting, if possible.   C Murphy to forward diary invite.

   ii. **Breast Implant Register & Patient Consent and Health and Care Bill 2021 – Medicine Information Systems – Extension of Provisions to NI**

   There was further discussion regarding the Breast & Cosmetic Implant Register (BCIR) and the obtaining of patient consent for data to be collected and held by NHS Digital, in order to facilitate tracing of patients in the event of a product recall/safety concerns, as well as any potential secondary use of data eg: to identify trends/complications related to the use of specific implants.

   PAC had previously considered that explicit consent should be sought, as patients would not normally expect their data to be held outside of N. Ireland.

   The possible use of the NI Honest Broker Service (HBS) to facilitate the transfer of anonymised/pseudonymised data to the Registry, via NHS Digital, to allow for the necessary monitoring, was discussed. Brendan O'Neill noted that there could be some issues with this as NI patients may receive treatment in other areas of the UK, which would not have access to the NI Health & Care Index number. Also, use of the HBS would not allow for the transfer of data for those patients treated within the

independent sector in NI.

Prof McClelland noted that patients receiving treatment in England would be subject to the arrangements under the Health & Social Care Act.

Prof McClelland also queried whether it would not be a reasonable request that all surgeons providing treatment within the independent sector in NI, fulfill confidentiality requirements by sending the relevant data to the NI HBS, as opposed to forwarding the required data to NHS Digital.

It was agreed that prior to issuing of guidance, PAC should meet with David Wilson, Department of Health, who is leading on the matter, to discuss the issue further in relation to patient consent. Brendan O'Neill agreed to follow up with David Wilson to schedule a meeting with PAC.

Action: Brendan O'Neill

4. **Chairman's Update:**

    i. **Use of General Practitioner Intelligence Platform (GPIP) to contact patients re Covid 19 status**

        Prof McClelland advised that he had been involved in recent discussions in relation to inviting clinically vulnerable patients, who had been identified as a close contact of a positive case of Covid-19, to participate in a clinical trial, where they would be offered new anti-viral medication. GPs would be alerted and asked to consider contacting those patients who had been identified as close-contacts and deemed to be clinically vulnerable. It was noted that only the relevant GP will make contact with the patients, with no third party involvement.

        The system will enable GPs to contact their patients, where they consider this to be appropriate, to advise them that they may benefit from the new anti-viral medication.

        Prof McClelland advised that he was content with the data encryption arrangements associated with the transfer of data to and from the Honest Broker Service and had no concerns re the potential for compromised data security or patient confidentiality issues. He considered the proposed arrangements in relation to this matter to be entirely secure and appropriate and that they would provide an enhanced level of care for patients.

        It was noted that the system for notifying GPs does not involve the Covid-19 App. The relevant triggers are a part of the existing Covid-19 contact-tracing programme.

        Further to discussion, PAC were in agreement with Prof McClelland and considered the proposals to be entirely appropriate.

    ii. **National Cardiac Audits**

        Prof McClelland provided an update in relation to NI's participation in a number of National Cardiac Audits, which had previously been halted to prevent personal identifiable information being transferred outside of NI, in the absence of the required legislation.

        Further to discussion with the Consultant Cardiologists involved, a means of collating cardiac audit activity via the NI Honest Broker Service had been successfully tested and developed, allowing for the required data linkage to enable NI's participation in the national audits.

Discussion is ongoing with the relevant HSC Trusts and the Department of Health in relation to securing funding to support NI's continued participation in these national cardiac audits.

It was noted that the successful use of the HBS for the above purpose is an exemplar for other national audits, in the absence of the required legislation, and has resulted in further similar discussions recently; including NI's participation in a national IBS programme.

It was also highlighted that the use of the HBS to undertake data linkage and allow for the flow of data in an anonymised form, has enhanced information security and data protection.

5. **Encompass Governance Issues ~** Dr Jimmy Courtney, Chair, Encompass Information Governance Advisory Council (IGAC) & Claire Staple, Encompass Team

Prof McClelland thanked Dr Jimmy Courtney and Claire Staple for attending the meeting to provide an update on the implementation of the Encompass system and the associated governance issues, which may also be an item for discussion at the forthcoming meeting of PAC with PDGs in September 22.

Prof McClelland asked that PAC be made aware of any patient confidentiality issues associated with the roll out of Encompass, including the potential for secondary use of information.

Dr Courtney and Claire Staple provided an overview of Encompass and developments to date, including:
- Background and overview of existing NIECR;
- Encompass is a HSCNI-wide initiative and will provide an integrated digital care record for NI – patients will be able to access their own information and use the system to communicate with their health and social care team, view test results and manage appointments;
- The expected benefits to both patients and healthcare providers were highlighted;
- The system will be delivered by Epic;
- An outline of the structure and governance arrangements was provided – a number of Advisory Councils have been established, including the Information Governance Advisory Council (IGAC), chaired by Dr Courtney;
- A number of Decision-making Groups and Workstreams are also being established, including for Information Governance; along with Focused Content Design Groups;
- Decision Groups will include representation from Subject Matter Experts – issues will be escalated to the relevant Advisory Council if required.

Prof McClelland thanked Dr Courtney and Claire for the informative update – discussion followed:

- There was some discussion regarding patient consent and also the increasing public awareness of the extent to which personal health and social care data is shared and accessed - impact of GDPR regulations; as well as increasing concerns re cyber-security and the potential for data breaches and hacking of personal data;

- PAC stressed the importance of ensuring the public are aware of developments in relation to the implementation of Encompass and plans for the future use of data; It was noted that the Epic Communications Team have been invited to the next meeting of the IGAC, to discuss a public awareness campaign re the implementation of Encompass;
- Governance/security measures within the system were noted, including:
  - Role-based access – users will only be able to view information which is appropriate to their role;
  - Tracking/audit mechanism will be in place to monitor access, with improved functionality in comparison to the existing within the NIECR;
  - The Epic Technical Team have provided an overview on the cyber-security controls which will be in place;
  - It was noted that the system will be hosted within BSO and will be subject to HSC security policy and data protection requirements.

- Prof McClelland referred to PAC's ongoing discussions with the NIECR Governance Group, and a small Working Group which had been established to discuss patient <u>opt-out</u> from the NIECR – lengthy discussions had taken place, including with patients who have expressed a wish to opt-out.
  It was noted that there are no proposals for patient opt-out from the Encompass system – it was highlighted that the duty of care to patients requires a health and care record to be retained. While the NIECR brought together a number of existing electronic systems, Encompass will provide a single health and care record, which is necessary for the provision of patient care.

- Dr Courtney confirmed that discussions had taken place with the Information Commissioners Office (ICO) in December 2021; an overview of the governance arrangements in place with the implementation of Encompass had been provided and discussion had included opt-out and the legality of this.
  Dr Courtney advised that the ICO had been invited to be involved more fully within the IGAC, however they were content with the current arrangements and for ICO to continue to be informed of significant developments and approached for advice, as and when required, should specific issues need addressed.   The ICO had been provided with the most recent version of the DPIA and will provide comment on this.
  In relation to public engagement, the ICO had encouraged the IGAC to use the existing forums and processes in place, including liaising with the Patient Client Council.

- Prof McClelland queried whether the IGAC had been made aware of any issues to date in relation to data security, patient confidentiality, data breaches etc, which those organisations already using Epic had already encountered.   Dr Courtney was not aware of any such issues, it was noted that Epic had been in place for a considerable period of time, in a large number of H&C organisations. Robust governance arrangements, policy and procedures are already in place with extensive experience to draw upon.
  Dr Courtney advised that further detail re the audit functionality within Encompass can be forwarded to PAC if requested. It was noted that any learning is continually incorporated within new software releases and system upgrades, with ongoing feedback and input from IGAC members.

- Eileen McKay (Deputy Executive Director, Social Work, BHSCT) advised that she had been involved with the relevant Encompass Governance Group in relation to social care. She highlighted the great onus which rests with the Decision Groups in ensuring that any issues which are relevant to NI are considered and addressed accordingly eg: ensuring appropriate confidentiality in relation to the adoption process and the need to ensure that original identity is not shared on the health and social care record. It was noted that this had been successfully resolved via the relevant Decision Group and had not required escalation to the IGAC.

- Eileen McKay stressed the importance of ensuring correct membership on the Decision Groups to ensure that the required expertise is in place to address issues as required, particularly in relation to social care. Claire Staple agreed to forward Eileen McKay a list of the existing Decision Groups and membership, for review and feedback – membership can be reviewed if needed.

Action: Claire Staple/Eileen McKay

- Claire Staple noted that social care issues are also being addressed in advance of the implementation of Encompass – a representative from Finland, with experience of using Epic in relation to social care data, will be attending the March 22 meeting of the IGAC.

- Brice Dickson queried the level of access and the amount of detail, which patients will have access to within their clinical record via the patient portal and whether the consequences of this had been considered. It was also queried whether consideration had been given to the implications of patients wishing to challenge or amend the detail within their records, should they feel the content is inaccurate. Claire Staple agreed to provide feedback on this.

Action: Claire Staple

- It was noted that Encompass will allow for increased communication between patients and healthcare providers via the portal, which may reduce the need for appointments/phone-calls.

- It was noted that there could be a difference between patients being informed of information via an appointment with a healthcare professional and actually being able to read their clinical information via the portal. The process for uploading clinical detail to the portal was queried – will Clinicians need to approve upload of information and is there a requirement for it to be relayed to the patient in a different format in advance? Claire Staple agreed to clarify.

Action: Claire Staple

- It was queried whether historical data will be migrated to Encompass and if there would be any impact for Clinicians should patients have access to view previous clinical letters. It was noted that this will be considered by relevant Decision Groups with input from

healthcare professionals.   There are currently no plans to scan paper records to Encompass.   Archiving of legacy e-systems, including the availability of the NIECR, will also be considered by Decision Groups.

- It was noted that patients may also have concerns as to who can access their personal data and it was agreed that role-based access will need to be implemented.

- Brendan O'Neill advised that Encompass will provide increased security of patient information, with improved functionality in the monitoring of inappropriate access to clinical records.

- Encompass will improve access to patient information for secondary uses, however it was agreed that further discussion is required in relation to how data will be used and this will be informed by the HSC Data Strategy.   It was agreed that public engagement is needed.

- Any queries in relation to gender reassignment will be considered by the relevant Encompass Decision Groups.

- It was queried whether Encompass has any existing functionality in relation to Advance Care Policy and if the wishes of individuals can be recorded, should they no longer have decision-making capacity eg: DNR and requests not to receive treatment. Claire Staple agreed to clarify.   Colin Harper asked if it was possible to be included in any future discussions regarding Advance Care Policy in relation to Encompass.

Action: Claire Staple

Prof McClelland thanked Dr Courtney and Claire Staple for joining the meeting and updating PAC on developments and welcomed further discussion between PAC and the IGAC, particularly from an Information Governance and confidentiality perspective.

Dr Courtney also welcomed further input from PAC to IGAC and agreed to contact PAC for advice on any relevant issues.

Prof McClelland confirmed that PAC had reviewed and commented on an earlier version of the Encompass DPIA.

There was some further PAC discussion in relation to the retention policy for clinical records. It was noted that retention and disposal schedules are already in place within the HSC.

It was agreed that having the correct professional representatives on the Decision Groups was a key part in the implementation of Encompass and patient representatives should also be included as relevant.

6. **Any Other Business**

Brendan O'Neill advised that work is ongoing to finalise the HSC Data Strategy, led by Dan West, Chief Digital Information Officer.

Competing demands and the impact of dealing with the current pandemic were noted. Work is progressing as far as possible.

7.   Dates for 2022 Meetings of PAC

- o   Thursday, 28th April
- o   Thursday, 7th July
- o   Thursday, 15th September (joint meeting with Personal Data Guardians)
- o   Thursday, 24th November