

**61<sup>st</sup> Meeting of the Privacy Advisory Committee**  
**Thursday, 7<sup>th</sup> July 2022 at 11:30am**  
**Microsoft Teams Meeting**

**Present:** Prof Roy McClelland (Chair), Brice Dickson, Colin Harper, Eileen McKay, Brendan O'Neill, Geraldine Reynolds, Ian Young

**1. Apologies and Welcome**

Apologies were received from Dr Clodagh Loughrey, Gillian Acheson and Clare Murphy.

**2. Minutes of the Previous Meetings – 20 January and 11 February 2022 (Encs 1 & 2)**

The minutes of these two meetings were approved.

**3. Matters Arising:**

**i. Ongoing discussion of the Personal Data Guardian role and responsibilities**

It was agreed that the role of PDGs, and who should fulfil it, should be raised at the joint meeting with PDGs on 15 September 2022.

**4. Chairman's Update:**

**i. National Cardiac Audits**

Prof McClelland explained the current position. Various audits, including the Cardiac Arrest audit, are awaiting progress. The intention is that the Honest Broker Service will be the repository of data in Northern Ireland, where it will be anonymized before being transferred to the national audits. There remains a decision to be taken as to who pays for the work involved in this. It was noted that funding for the HBS is secure only until March 2023, but that the Department's intention is to fold it into a larger 'Data Institute'. Colin Harper suggested that the service be given a name that continues to reflect its purpose. 'Trusted Research Environment' may be the chosen name in England.

**ii. Minutes of 57th PAC Meeting ~ 21st January 2021 – Requested Amendment re NIECR Opt-Out (Enc 3)**

It was agreed that in the minutes of the meeting on 21 January 2021, under item 4(i) the following paragraph:

'The Chair of the NIECR Steering Group had written to each individual who had expressed their wish to opt-out, to inform them of the implications of this decision on their care and the impact of Clinicians being unable to view their records.'

should be replaced with the following paragraph, to reflect more accurately what the original paragraph was intended to convey:

'The Chair of the NIECR Steering Group had written to eight of the nine individuals the working group had been asked to consider and who had expressed their wish to opt-out, to inform them of the implications of this decision on their care and the impact of Clinicians being unable to view their records. The ninth individual had been spoken with directly by Mr Les McLean, eHealth Operation Support, ITS, Business Services Organisation.'

- iii. Prof McClelland informed the Committee that Dr Arjun Dhillon had been appointed as the new chairperson of the UK Caldicott Guardian Council.

## **5. Independent Neurology Inquiry – confidentiality issues**

Prof McClelland shared his observations on the INI report, highlighting that it deals a lot with doctor, rather than patient, confidentiality (a topic beyond the remit of the PAC) and that it focuses on data protection, especially the GDPR, without referring to the common law rules on confidentiality. He drew the Committee's attention to, in particular, Recommendations 12, 13, 16, 17 and 18 in the INI report.

Brendan O'Neill pointed out that the report deals with the period 2005 to 2016 and that there had been a lot of developments on data protection since then, including the development of the NIECR. The report is mainly about doctor management and poor record-keeping within the independent healthcare sector.

Dr Ian Young and Colin Harper each stressed that patient safety is always a factor to weigh in the balance when disclosure of health data is being contemplated. It may not always be paramount, but in the public interest it will normally take precedence.

It was agreed that Prof McClelland would write to the Department offering the PAC's advice in relation to some of the recommendations in the INI report.

**Action: Prof McClelland**

## **6. Agenda Options for Joint Meeting with PDGs and IGAG – 15 September 2022**

This will be an online meeting, probably for an hour-and-a-half. Possible agenda items considered were:

### **i. Personal Data Guardian role and responsibilities**

As noted under 3 i above, the role of PDGs, and who should fulfil it, will be part of this discussion. It was also agreed that the role and impact of the PAC should be referred to.

### **ii. Consent and the disclosure of patient information**

Given the changes in PDGs over recent years and the topicality of requests for information disclosure for secondary uses, including the recent INI report, it was agreed that the Code of Practice guidance on consent and the disclosure of patient information would be a useful refresher topic.

### **iii. Encompass - governance Issues ~ Dr Jimmy Courtney, Chair, Encompass Information Governance Advisory Committee (IGAC) & Claire Staple, Encompass Team**

It was agreed that this item could be dropped from the agenda of the joint meeting, due to likely shortage of time at the meeting.

## **7. Update on Legislation**

Brendan O'Neill noted that the Department was in the process of recruiting someone to take further the work required to be done on preparing the regulations required under the Health and Social Care (Control of Data Processing) Act (NI) 2016.

## **8. Any Other Business**

Prof McClelland announced that he would be standing down as Chair of the PAC at the end of this year. Thereafter Colin Harper will take over as Chair.

**9. Dates for 2022 Meetings of PAC**

- Thursday, 15th September (Joint Meeting with Personal Data Guardians and IGAG)
- Thursday, 24th November