IIGOP Meeting 24 March 2015, Richmond House, London

Panel Members present:-

Dame Fiona Caldicott - Chair John Carvel Dr Alan Hassey Eileen Phillips David Riley Professor Martin Severs Anne Stebbing Mark Taylor Richard Wild

In Attendance:-

Joanne Bailey (Item 6 only) Lindsey Blake David Knight on behalf of Mark Davies IIGOP Sponsor (Agenda item 4) Kathy Holland

Guest Speakers:-

Nick McGruer and Louise Pasqual - Department of Work and Pensions Martin Dennys - Genomics England

1. Welcome to Panel Members & Apologies

Apologies received from Ian Atkinson and Janet Davies.

2. Declarations of Interest

Mark Taylor expressed a declaration of interest with regard to Genomics - Agenda Item 10.

3. Minutes Actions & Decisions from Previous Meeting

The minutes of the last Panel dated 2 February 2015 were approved pending that Alan Hassey be named as Chair at that meeting and not Dame Fiona.

John Carvel asked who was responsible for monitoring against Caldicott 2 recommendations going forward.

3.1. Action: The discussion regarding monitoring was agreed to be considered at the next steering group.

4. Sponsors Update

David Knight advised that no further progress had been made on the Three Pillar Information Governance model. However, that IGOG (Information Governance

Oversight Group) had been reformed as a governance mechanism for the NIB's (National Information Board) work stream processes. David Knight advised that the need for a governance steering group had been recognised and the plan was to include NHS England, the Department of Health and IIGOP.

4.1. Action: David Knight suggested that a discussion should take place with IIGOP on the Three Pillar Model pre the election.

David Knight advised Panel that IIGOP should be put on a legislative basis very soon after the May 2015 Election.

David Knight advised Panel that the latest response to the consultation on the DH Data Regulations was due for publication within the next two days. The Chair stated this had not been circulated to Panel. David Knight apologised for this omission.

4.3. Action: David Knight would endeavour to share the latest Response to consultation on Protecting Health and Care Information (DH DATA SHARING REGULATIONS) with IIGOP.

Concern was raised with regard to ambiguity on data services for commissioners. David advised that the programme currently involved CCGs and NHS England but not Local Authorities, and that a solution was being sought for the population of patients and service users as a whole.

Mark Taylor requested early engagement with HRA and CAG and highlighted a communication issue raised at the Pioneer Workshop held on 23.3.15 where Pioneers had been given advice not to speak to CAG over a fourteen month period.

4.4. Noted: IIGOP noted concerns about lack of Department of Health communication on Pioneer process.

David Knight advised that Government Digital Services have given the go ahead for the new NDG web pages on DH.gov.uk.

The Chair raised a concern that IIGOP do not have the facilities or resource to carry out the work the Secretary of State for Health requested in November 2014 due to the funding and hosting position for April 2015 not yet being confirmed and in place.

5. Guest Speakers - Department of Work and Pensions

Nick McGruer and colleague Louise Pasqual presented their paper on Fit Note Data comprising a technical and legal solution that enables HSCIC to extract fit note data from GP IT systems on DWP's behalf, giving named staff access at GP-practice level and publishing publicly at Clinical Commissioning Group (CCG) level in line with the commitment in the Government's Open Data Strategy.

MT made the point that thought needs to be given to the evolving use of the data.

IIGOP were interested in and supportive of this and commented on that fact that this will be pioneering some of the fair processing and objections work involved in this extraction.

6. GPES IAG, SCCI, DAAG & DDAG

AH introduced this item (Joanne Bailey also attended for this item).

As Chair of DAAG, AH relayed his responsibilities in trying to bring transparency about data and increase the pool of its independent members. HSCIC information governance systems needed to be changed following the Partridge Review, HSC hearings of 2014 and the Care Act 2014.

Martin Severs gave an in-depth explanation of the background and workings of the Standardisation Committee for Care Information (SCCI).

Noted: IIGOP thought that the IAG /SCCI proposals should be considered by NIB.

Noted: HSCIC Board should consider the proposals for the IAG / DAAG > DDAG transition and that DFC would welcome the opportunity for further discussion with Kingsley Manning.

Noted: That the proposals should be presented in a joined-up & coherent manner for consideration and consultation with key stakeholders and the public

- 6.1 Action MS commented that DFC's recommendation that it should go through NIB is a useful route and will try to formulate feedback into a mechanism from SCCI to NIB.
- 6.2 Action MS to reflect on discussions and send a note to Panel to then take it to HSCIC's Board. This would join a system issue and a Board issue Panel members to send thoughts to MS by Sunday evening (29.4.15).

7. National Data Guardian Panel Transition

Richard Wild advised Panel there was nothing further to report and that the funding and hosting position is still in progress.

8. UK Council of Caldicott Guardians' Workshop Update

The Chair advised Panel that the workshop held on 23th February was positive and that it was agreed that another Workshop be scheduled in late April 2015.

The Chair advised Panel that as a result of the positive feedback from the Workshop she has had a discussion with Peter Hall to discuss how the UKCCG Agenda can be progressed.

9. Panel Members Views and Thoughts

9.1 IGA Proposal - Review of the Care Record

Panel members considered the updated Review of Care Record paper originally presented at Steering Group on 3.3.15. It was agreed that the IGA should continue with its Care Record proposal but should share a more detailed plan with timescales as soon as possible.

9.1 Action: Lindsey Blake to feedback this outcome to the IGA.

9.2. Patient Voice Paper

Panel considered Paper 9.b. Patient Voice. It was agreed that the name of the process be changed to incorporate the public's view to encompass an overall informed view. In addition, the process should reflect national public deliberations, testing engagement for and within the public domain. It was recommended that the Nuffield Council on Bioethics' Report's section on public engagement could be a good steer.

The Chair thanked David Riley for his Public Voice paper and recommended that no further action be taken pending further work on the public engagement programme with NIB work stream 4.

10. Guest Speaker, Genomics England.

Martin Dennys was invited to Panel to present an overview of the 100,000 Genomes Project together with the IG challenges Genomics England face.

11. Care.data Update

The Chair advised Panel that she had been assured no care.data communications would be published prior to the May 2015 election and that her letter on behalf of IIGOP to Tim Kelsey dated 19 March, 2015 highlighting concerns with the materials, had played a key factor in the decision.

12. Media Update

Eileen Phillips recommended that an interview be set up with HSJ once the National Data Guardian Panel is launched and agreed by the new Government.

Eileen advised Panel of her forthcoming retirement from the HSCIC. The Chair thanked Eileen for all her hard work, in particular on behalf of IIGOP. Eileen advised that she would continue as a Panel member until September 2015.

13. Any Other Business

Alan Hassey reminded the Chair that a reply to Joanne Bailey's recent email was pending.

That a discussion on Panel Members should be placed on the Agenda at the Steering Group scheduled on 14th April, 2015.

13.1 Action: IIGOP comments on the proposed NDG Terms of Reference to be sent to David Riley and Lindsey Blake.

DATE OF NEXT PANEL 18 May 2015