

Draft NIMB paper – IG Framework

Progress to date

- The Statement of Intent issued in October 2017 included a commitment to *‘develop a more transparent framework for how we manage, use and share health and care data and to ensure everyone involved, most importantly the public and patients, understands the way we use and share data’*.
- An Information Governance Project group has been established and a number of stakeholder sessions took place in January and February in order to inform the requirements, the current understanding and expectations for this work.
- A paper setting out the current Welsh Information Governance framework – Implemented standards, solutions and governance is attached at Annex A.
- During the spring the group met with colleagues in England and Scotland, the Information Commissioners Office Wales, the Confidentiality Advisory Group, members of Welsh Information Governance Board and other key stakeholders in Wales. This work led to the development of an options paper (attached at annex B) for a strategic approach to how appropriate and proactive information governance can support the use of health and care data in Wales.
- This paper has been shared and presented to key stakeholders across Wales, including:
 - Welsh Government Health and Social Services Group policy leads;
 - Welsh Information Governance Board;
 - Information Commissioners Office in Wales;
 - Information Governance Managers Advisory Group;
 - Informatics Planning and Delivery Group;
 - Public Health Intelligence NET;
 - All Wales Heads of Information Services;
 - Bio banking Task and Finish Group;
 - Members of the Confidentiality Advisory Group.
- The paper recommend option 4, to implement the ‘data promise’:

“No identifiable data about you will leave health and care without either your explicit consent or legal requirement for that to be done (such as for safeguarding). Health and care services will routinely, appropriately and securely share your identifiable data within health and care to deliver high quality, safe and integrated care”.
- It has been widely considered that this option presents the most strategic and far reaching solution, in response to the Parliamentary Review and the Welsh Government’s long-term plan for the future of health and social care in Wales, A Healthier Wales.

- The majority of stakeholders agreed that this option would seek to put health and care in Wales on sustainable information governance setting for the long-term and supports the philosophy of a long-term view of a unified health and care system for Wales, centred on the individual. It acknowledges the need for multiple professionals to see and know what is happening around an individual so that they receive the appropriate level interventions to support them. It is the basis of an updated policy approach which delivers “privacy by design”.
- Although there was significant support for the data promise, this was not universal, with GPC Wales considering that following and joining England’s opt-out (option 2) was the correct option. A few members of the research community also share concerns that it would be unlikely to be in Wales’s best research interest to diverge from England, if England’s opt-out scheme is a success.
- There was no support for option 1 – Strengthen existing arrangements (maintain the status quo) or option 3 – Develop separate opt-out scheme for Wales.

Next Steps

- Undertake work to better understand the impact, resource, technical and legal ramifications of Options 2 and 4. For either option this will include making legal changes e.g. *the functions of the Secretary of State under section 251 (control of patient information) of the National Health Service Act 2006*; having a nationwide conversation with the public and professionals and adapting current National Information Governance Guidance.