

Belfast City Hospital
51 Lisburn Road
Belfast
Bt9 7AB
6th August 2015.

Re Health and Social Care (Control of Data processing) Bill

Dear Ms Austin,

Thank you for your invitation to respond to the proposed Health and Social Care (Control of Data Processing Bill). There is a clear need for this bill, to formalise and clarify governance issues around the use of health (and social care) data to monitor, improve and understand our health and social care systems. National audits, making use of English data, have been associated with a 10% improvement in survival for lung cancer, with a concomitant increase in patients receiving curative intent surgery. This is a profound improvement in survival and care, by far overshadowing improvements in survival seen in most recent drug trials. Monitoring of healthcare services in Northern Ireland, as per these national UK audits, and benchmarking against UK regions and Trusts will undoubtedly improve understanding and drive up quality and outcomes for the people of Northern Ireland. Failure to engage with these audits will not only be a missed opportunity, but most likely result in Northern Ireland falling behind in health care provision relative to UK regions.

The bill as proposed seems to make provision for the gathering and analysis of the relevant data (subsection 1). It is important that the legislation allows organisations such as the Northern Ireland Cancer Registry to handle, analyse and report on the data. The NICR is a key partner to us in the processing and analysis of audit data for the national lung cancer audit (NLCA), which has produced the benefits for England listed above. It may be that the bill needs some rewording to facilitate this partnership. The development of an oversight committee is in line with the other UK nations and seems a reasonable provision (subsection 2). The constitution of this committee will be key to its ability to function and deliberate on the diversity of applications it will, hopefully, receive. I understand that further thought is to be given to this aspect of the proposed structure.

Yours sincerely,

Dr Jonathan McAleese on behalf of NICAN (lung subgroup).